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ABSTRACT

Reported is a study to describe how 12 groups of parents of handicapped children in Oregon engage in political democracy; and to identify some of the organizational, strategical, and attitudinal factors which maintain and sustain the participatory process. In an introductory chapter on the purpose and scope of the study, it is noted that data is presented on local parent groups politically active in seeking to effect changes in educational policy for handicapped children. In a review of the literature (chapter II), sections cover the pros and cons of participatory democracy; typologies, structures, and functions of voluntary organizations; and parents' role in the determination of educational policy. Summarized in chapter III are the nature of special education, abuses of special education programs, professional organizations' responses to such problems, and the status of Oregon legislation regarding handicapped children. In chapter IV, the background of the parent groups is examined, and some general characteristics shared by all groups (such as spontaneous expression of feelings) are discussed. Presented in the chapter on data collection (chapter V) is information on methodology (a case study approach) and a synopsis of data from interviews with 36 group leaders and active members. Examined in chapters VI and VII are recurring organizational and strategical themes (in such areas as membership, leadership, and professionals' roles) and sustaining attitudinal themes (which include the areas of accomplishments, legitimacy, and idiosyncratic needs). In a final chapter, it is concluded that the groups studied seemed to work; that their political activities resulted in changes. Among appendixes are an interview outline, information on five national parent organizations, and a list of groups interviewed. (SBH)

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POLITICALLY ACTIVE PARENT GROUPS OF HANDICAPPED CHILDREN:

A STUDY IN PARTICIPATORY DEMOCRACY

by

PEGGY LOUISE LARSON
and
BEVERLY ARRAIMANNAH NELLIGIN

A THESIS

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Research for this study and development of the document were conducted jointly by Peggy Larson and Beverly Melugin. A combination of effort was undertaken with the express purpose of producing a single study in order that the subject--elements of participatory democracy as exemplified by parent groups of handicapped children--be treated as a whole, with all its interrelated parts presented together. Citations for preparation of individual sections are given where appropriate.

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Self-interest associations are nothing new in the United States. They number into the tens of thousands and cover every conceivable human concern. The parents of handicapped children, in organizing membership associations to help solve their common problems, are therefore following an established American pattern.

Joseph H. Levy in Parent Groups and Social Agencies

CHAPTER I

INTRODUCTION

Purpose and Scope of the Study

The purpose of this study is to describe how groups of parents of handicapped children in the state of Oregon engage in participatory democracy, and to identify some of the ingredients that maintain and sustain the participatory process.

The study first reviews literature on participatory democracy, discussing the concept and its importance, as well as some of the problems encountered by groups who would engage in the participatory process. The voluntary organization as a vehicle for participation is reviewed, and structures and functions of self-help organizations are examined in detail. A review is also made of a particular instance of individuals wishing to participate in policy decisions: that of parents' attempts to influence educational policy. Parental efforts against the educational establishment, the phenomenon of community control of schools and the growing movement toward consumerism in education are discussed.

To give an idea of some of the problems that parents of handicapped children face in regard to securing educational changes, information is presented on the background and present status of special education. A review is then made of the origins and accomplishments of the nation-wide movement of the parents of the handicapped, along with a delineation

of some general characteristics of these organizations as noted by other writers.

Data are presented on twelve local parent groups, all of which were politically active, seeking to effect changes in educational policy for handicapped children. The groups are looked at from the point of view of two considerations: those factors which have a bearing on the political efficacy of the group and those which sustain individual participation. In order to better understand group dynamics which bear on political efficacy, an analysis of organizational characteristics and strategies as manifested by the groups is presented. In order to attempt a determination of what sustains individuals' participation, variables rising out of members' attitudes toward their own involvement are identified and discussed.

The study concludes by drawing inferences from the parent organizations studied which could be applicable to other groups engaging in participatory democracy.

Background and Rationale

Intertwined in democratic political theory is the concept of participatory democracy.

In its broadest sense, participatory democracy means people directly involved in making the decisions which affect their lives, decisions which relate to the ways by which people govern themselves.

The fragility of this concept is also a recurring theme. Within the context of the present extremely large and complex governmental framework, keeping participatory democracy alive has been of major

concern. In the last few decades there have been attempts by consumer groups to build in some participation of governmental services and programs, and where grass roots organizations already existed, federal guidelines have often sought to ensure their inclusion in local policy decision making.

One specific manifestation of participatory democracy is the voluntary organization, a special interest group formed to work for a particular cause of concern to its membership. Such groups, composed of persons who seek to influence policy regarding their interests, can be powerful political forces. Such groups, also, can embody the essence of the rewards of participatory democracy for their members.

The focus of this study is on the special groups which have formed by parents of children who are handicapped. There are two major reasons for making these groups the focus for a study in participatory democracy. The first reason is to explore and identify factors of the participatory process.

A writer who has examined parent groups of the handicapped in some detail concluded that he was encouraged, after his study, to see the democratic process still in action.[1] By looking at how these groups work it should be possible to gain insights into how participatory democracy works.

The staggering and heartbreaking experience of having a handicapped child has brought voluntary organizations of parents together to work with unusual energy in seeking services and rights for their children. Not only have these groups had success in shaping social and political

policy, but they have also provided a means whereby the sense of helplessness against a powerful, unresponsive governmental structure can be overcome.

Not all voluntary groups have their roots in such distinctly traumatic and charged atmospheres, although, frequently, crisis situations do produce unusually energetic citizens' groups in their wake. However, the presence of continuing problems--physical and mental handicaps, poverty, social injustice--to which responses need to be made, calls for the presence of concerned groups of people able and knowledgeable to participate in the solution to these problems. It calls for those affected to have, besides the capability, the conviction borne of experience that they can, themselves, help shape their world.

Unfortunately, in many instances, very concerned groups have been unable to successfully mobilize political power, have met with failures, and have been frustrated and disillusioned by their experiences. Often these have been parent groups seeking to change educational policy for their children.

By looking at the organizational characteristics and strategies of groups of parents of handicapped children, it should be possible to identify some practical information applicable to other groups, information to enhance the participatory process. Similarly, by studying groups members' feelings about their participation, it should be possible to gain more of an insight into the meaning of participatory democracy for the individual, and to identify those factors responsible for sustaining individual involvement.

The second major reason for focusing on these parent groups pertains directly to meeting the special needs of handicapped children. Of the estimated seven million handicapped children in the United States, only about 40 percent are receiving appropriate education and services.[2] Many thousands of children are still being legally excluded from an education. Although many states are now passing mandatory legislation--laws which assure a free public education to all children, no matter their handicap--the means by which such legislation can be implemented are often lacking. Even when litigation to secure the rights of handicapped persons has been successfully brought, parents have found this no guarantee that services will be forthcoming. There continues to be a pressing need to mobilize effective parent power.

This chapter was prepared by Peggy Larson.

CHAPTER II

REVIEW OF LITERATURE

Participatory Democracy

The concept of participatory democracy has long been perceived as a fundamental element of the American democratic form of government. A concern for the participation of individuals in the processes by which the community is governed has marked a great deal of democratic theory: there is major speculation whether active participation in the governance process is presently possible, whether it ever was possible, whether it is even desirable, given the extremely complicated technological order sustaining modern existence. But whether it is workable or not, and whether it is a myth or not, there is general agreement that belief in the concept alone is a major force for sustaining belief in the democratic form of government itself. Belief that participation in the decision-making processes that affect one's life is legitimate, is, moreover, expected and is an individual's right remains, even if the actual form of participation is so limited as to be negligible. Belief that, at any time, participation is possible is of tremendous importance in keeping alive the individual's faith in the democratic system.[1]

When it actually takes place, when individuals are actively involved with others in helping to shape their environment, on a large or small scale, classical democratic theory has a lot to say about the intrinsic

value of such participation. The act of participation is seen as directly affecting the individual: it is an educative process. People's views become wider, their tolerance greater, their capacities increased for understanding and making intelligent decisions. One's own conduct becomes perceived in terms of social consequences. A concern for one's fellow human beings, a sense of community and, above all, an increased awareness of one's own value and worth as a human being are the result of participation.[2]

Classical democratic theory is probably not occupying a prominent place in most people's thoughts as they go about their lives. However, the benefits that accrue to the individual as a result of participating in decision-making activities have been studied, they do exist and they are real.

Factory workers who began coming together, initially as a social group, developed a feeling of cohesiveness and the beginnings of an organization to discuss, and later confront, their patterns of control. Not only did they overcome their sense of powerlessness, but they began to experience a sense of power over their own destinies.[3] From this relatively small scale form of participation, statements arise, such as the following: "...[I]f we are concerned about freedom we will want to determine our own destiny. If we care about democracy we will not be content to have our prosperity determined by technological decisions in which we have no say...." Workers' control is not seen as an end in itself, but as part of a process of extending a democracy of participation.[4]

In today's terms, benefits to individual participants help to reduce the alienation, to halt the depersonalization[5] of present existence in a technological society. When individuals are engaged in making decisions with other persons who share the same situation, apathy and helplessness are reduced, and personal identity is heightened.[6] "Only participatory democracy can offer an alternative to the violence born of despair by allowing disadvantaged minorities to affect directly decisions which shape their lives."[7]

Particularly as related to problems dealing with quality of life--those problems which, so far, elude the ability of bureaucratic offices to adequately answer--can participatory democracy with its concept of collective wisdom arising from many points of view provide solutions. Participatory democracy is seen as providing the means by which society can remain sensitive to social needs and concerns and can have the resiliency to respond creatively to emerging social problems.[8] In turn, it expands the individual's own knowledge and feelings of self-worth.

There are pitfalls, however. A unit of people participating together to effect decisions can be undemocratic. The group may put excessive pressure on its members to conform; group leaders may allow the group to be manipulated, either by a few of its own members or by outside forces. Even "provision for grass roots decision-making can often mean effective manipulation...first, isolation of subjects by undermining traditional voluntary associations and second, promotion of pseudo-communities...designed for manipulation of membership."[9]

Parents who have demanded control of the schools often get an advisory council made up of unrepresentative "community leaders."[10]

While token participation may be seen by some as worse than non-participation, having the effect of taking off pressure, or cooling-out, and thus essentially dissipating the power of an opposing group, even this form of participation is a foothold, a recognition of the existence of other opinions. The danger lies in failing to continuously communicate group and individual feelings, and in letting fears of cooptation lead to paralysis.

Internal characteristics of a group which serve to nullify participatory democracy may be stickier problems. Pressure for members to conform to certain behaviors, particularly when the group is small, stifle the workings of participatory democracy. The group may, in such cases, split into factions which are more meaningful for the members. However, one risk of this may be realization of a painful fact of political life: those "who are not organized and who lack access to wealth and power have no voice...."[11]

The phony community-of-interest group is even more alarming, in that participants may be unaware that they are pursuing nonmeaningful goals, and, lacking the conviction associated with real concerns, allow others to choose for them. True voluntary associations "form spontaneously because of pressing needs to which the central system is irrelevant or antipathetic."[12] Forced participation or the absence of a real sense of involvement can easily lead to relinquishment of the participatory role.

In spite of its weaknesses, potential abuses and the limited use to which it is put in the opinion of some, participation in determining the manner and form of governance continues to be valid: people continue to form interest groups, many groups endure for long periods, and individuals continue to involve themselves in the group process. There are obviously rewards for both the individual and the group.

This section was prepared by Peggy Larson.

Voluntary Organizations: Typologies, Structures and Functions

There has been a proliferation of voluntary organizations within recent years. They are referred to under such headings as: voluntary associations, self-help organizations, self-organized groups and interest groups. They exist in virtually all aspects of society. Contrary to what many people think, voluntary organizations are not an American invention of a century or two ago influenced by the famous work of deToqueville--they have been around for about ten thousand years.[13] However, voluntary organizations seem to be more prevalent in industrialized societies. Literature on the origins of volunteer organizations indicates that as society becomes more complex and heterogeneous, individuals seek alternatives to maintain their individuality and identity by associating with others who have common goals and values. One writer provides a good example of this in relation to the effects of urban life: "Being reduced to a stage of virtual impotence as an individual, the urbanite is bound to exert himself by joining with others with similar interests into organized groups to obtain his ends."[14]

The emergence of bureaucracy and professionalism in the fields of human service and education have produced another societal complexity along these lines. The professional exhibits an attitude of "knowing what is best" for the client or student. The bureaucratic system, with its well-ordered sequence of events and procedures, offers little or no access to the individual. Consequently the individual becomes the victim of the system. This has been the case with racial minorities,

parents of handicapped children, the poor, alcoholics, drug addicts, homosexuals and women. "One of the most fundamental issues involved in self-help by stigmatized individuals is that those who experience the condition perceive and define it differently than does the prevailing society."[15] This has given rise to a large number of stigmatized individuals joining forces in organizations in an effort to change how society views them and to improve their own self-image as a means of dealing with society.

The literature of complex organizations focuses on internal structure and relationships of the larger more formal groups with institutional functions--factories, hospitals, schools, public and quasi-public agencies--while the study of voluntary organizations commonly deals with the question of participation and community function of the smaller, local and institutionally less significant groups--clubs, leagues, "societies," lodges.[16] Two reasons why these concerns have been separated are:

1. It is difficult to include voluntary organizations in the general definition and classification system of complex organizations because of their unclear boundaries, varying involvement of members and their particular relationships with the environment.[17]
2. Data on voluntary groups has not generally been collected from an organizational analysis point of view.[18]

These reasons do not negate the need for an interdisciplinary approach to the organizational aspects of voluntary groups.

Three Typologies

The organizational characteristics of voluntary groups are critical for developing a framework from which to view the consequences of such groups, and especially for this study in regard to the phenomenon of participation. Further, classifying these characteristics can be equally important as a means of ordering information to gain additional understanding of the structures and functions of voluntary organizations. The great danger in most classificatory schemes is oversimplification if they are based on a single characteristic.[19] However, typologies derived in this manner "...can be expanded indefinitely as some new factor is seized upon to indicate an additional class."[20]

Four typologies of voluntary organizations based on Assumed Value Function are offered by Warriner and Prather. Working on the premise that collective functions (those consequences of activity which are relevant to the collectivity as a whole or common to its member) produce values, four types of value functions are identified: (1) pleasure in the performance: bridge clubs, painting clubs, ski clubs; (2) sociability or desired communion with others: "The Happy Hour Club," "Social Circle;" (3) symbolic or reaffirming a valued belief system: certain lodges, some churches, religiously oriented sororities; (4) production or activities which produce goods, services, or change: League of Women Voters, service clubs, political action groups.[21]

Gordon and Babchuk pose a typology of voluntary organizations utilizing three criteria of classification:

1. Degree of accessibility. Organizations can be separated into two classes--high and low accessibility. High accessibility--YWCA, Girl Scouts. Low accessibility--Daughters of the American Revolution.
2. Status conferring capacity--high and low status. High status--American Sociological Society. Low status--Synanon.
3. Functions--expressive, instrumental, or expressive-instrumental. Scuba Diving club, Photography club--expressive. National Women's Political Caucus, Common Cause--instrumental. Association for Retarded Citizens, National Organization of Women--expressive-instrumental.[22]

The recent flourishing of self-help organizations formed by individuals with a common problem and performing multiple services to their members on a local level, outside the framework of the usual community services, has led Katz to develop a typology for classifying these groups: assimilative, separative, and mixed. "This typology refers to the goals of self-help groups in terms of their relationships with and use of other community agencies and professionals. Under this scheme, Synanon might be categorized as separative, United Cerebral Palsy as assimilative, and Alcoholics Anonymous as mixed."[23]

The foregoing typologies present some examples of how voluntary organizations may be classified. They are by no means all inclusive since it would be beyond the scope of this study to do an exhaustive review. Rather, they are meant to provide an overview of some types of voluntary groups and be applicable to parent groups of the handicapped.

Structures

All organizations make some provisions for continuing their activities directed toward achievement of goals. They establish routines for activities such as task allocation, leadership, planning and coordination. These routines constitute the organization's structure. The fact that activities can be arranged in a number of ways means that organizations have different structures and in some ways each organization can be considered unique. Factors such as organizational objectives, size, geographical local, societal attitudes and technology all contribute to the variation of these structures.[24]

The structures of voluntary organizations are as varied as any other organization--industrial, business, governmental. While these variations exist, voluntary organizations also possess structural features common to other types of organizations. Voluntary organizations are often viewed as being more informal or perhaps less bureaucratized or professionalized than other organizations since they are voluntarily joined by individuals and are not essential to one's survival in the same sense that most adults must be members of organizations for monetary purposes. The degree to which voluntary organizations are considered formal or informal is contingent upon many of their structural characteristics.

Combining the dimensions presented by several organizational analysts[25] and the experience of this writer a fairly eclectic set of structural features of voluntary organizations can be discussed.

Membership varies from a high tolerance for heterogeneity (diverse social class, educational, occupational, ethnic, religious affiliations) to homogeneity (ascriptive attributes such as same age, sex, social class, stigmatizing condition). The membership region may be flat to hierarchically ordered statuses. Participation may be nominal to active. The locus of power in regard to participation may be the top down, elitist, corporate-type or the "bottom up," participatory democracy type. The degree of fission potential varies from a tendency to splinter or break off to a cohesive, unified, tightly fused group. Accessibility to membership may be very open to very limited depending upon the exclusiveness of the group. There is a degree of voluntariness vs. coerciveness for joining a group: an individual may feel it is socially mandatory for economic, professional or prestige reasons to join; there may be little or no pressure to join; there may be social pressure not to join; there may be social or legal prohibition against joining.

Production, instrumental and self-help groups demonstrate a high degree of interrelationships with the environment. Assumed kinship, secrecy, ranked statuses and ritual are all characteristics of symbolic organizations. Sociability groups get their structural characteristics through interaction of their particular individuals.

Governance. This area can be divided into two parts--leadership and written controls. The leadership or control region may be flat or virtually nonexistent. In this case the main function of officers may simply be to collect membership dues annually, make arrangements for

meeting places or other group activities. Officers seldom make any decisions that have binding consequences for the organization. Conversely the leadership may be hierarchically ordered. There may be many officers, boards, statuses and a staff. The officers, boards and staff members may deal directly with or independent of the membership. The type of leadership can range from charismatic or personalized to rational, formal or bureaucratic. The degree of leadership accessibility may be tightly controlled, high leader stability to democratic, openly accessible with low leader stability. Relating to all of these characteristics is the degree of experience and resourcefulness that any leader may possess.

Voluntary organizations may or may not have a written constitution or by-laws which influence governance. Some groups operate completely independent of any written rules but may have common understanding of how to proceed. There is some evidence that the degree of formalization or bureaucratization affects whether or not a group feels it necessary to have a written document from which to operate. Relatively loose, amorphous, unstructured groups tend to feel they are not absolutely necessary while complex, highly structured, differentiated groups feel they are vital. However, some informal, unstructured groups find it necessary to have a constitution in order to gain tax exempt status and may adopt one solely for this purpose.

Size. Voluntary groups may be small, medium or large. There are several interrelated factors that may influence size such as:

1. Functions, status conferring ability, accessibility--social, educational, professional, geographical.

2. Organizational growth rate--rapidly growing, stable, declining, withering, dying.
3. Age of organization--young, middle aged, old.
4. Length of intended time span--short-term, crisis-oriented, ad hoc, ephemeral, continuous, long-term, permanent.

Frequency of meetings. Factors such as functions, size and age influence how frequently voluntary organizations hold meetings. They may vary from continuous, weekly get-togethers to cyclical (every so many weeks, months, years). Young organizations may have frequent meetings simply because there is a great deal to accomplish in the initial stages. Social groups and groups whose functions are primarily emotional support may meet often to provide continuity for members. Large groups such as the National Child Welfare League or the National Geographic Society meet annually and in some instances the total membership never meets.

Affiliations. There may be transnational, national, regional, state, district, multi-county, multi-city, county, city, or neighborhood affiliations. Groups may almost completely isolate themselves from other groups or they may be highly dependent upon affiliation. The degree of variance may depend upon their independent operating capacity or their functions. If a group has good mobilizing skills, good resources and past experience to draw upon they may not feel the need or want to affiliate. However, if the primary goals of a particular group are to produce change, it may view affiliation as an essential element for gaining strength in which to accomplish these goals. Some

productive or instrumental groups may be free from affiliation but have extensive interchange with the local community environment in matters relating to money, personnel and services.

Amount of wealth. The size of budgets of voluntary groups range from small to large. The amount of the annual budget is influenced by the wealth of the membership, the size of the group, investments, endowments, real estate, fund raising capabilities and qualifications for United Funds and governmental grants.

Functions

All organizations have functions just as they all have structures. Functions are referred to as goals, aims, purposes, or objectives for which a group of individuals come together. The functions of volunteer organizations are as varied as those found in other types of organizations. Dimensions of functions are crucial for understanding the differences among voluntary organizations.

Instrumental. The instrumental function is oriented toward "...activities which take place outside the organization. It seeks to maintain a condition or to bring about change which transcends its immediate membership."[26] "Certain groups do not exist primarily as an end in itself, but serve as social influence organizations designed to create some normative condition. Such groups exist in order to attain goals that lie outside the organizations themselves."[27] "...[i]nstrumental groups are organized expressly to change the social order or maintain the status quo, to insure that vital services will be available to persons

in society, to help distribute power at different levels, to educate, to persuade, etc."[28]

Expressive. The expressive function

> ...provides the framework for immediate and continuing gratification to the individual....These groups perform a function primarily for the individual participants through activities confined and self-contained within the organization itself. More specifically, they provide the opportunity for carrying on activities, such as recreation, of direct interest to the participants or to help provide satisfactions of personal fellowship. Also included in this category are honorific or status conferring organizations....In the main, the orientation of the group is not to the attainment of a goal anticipated for the future but to the organized flow of gratifications in the present.[29]

Expressive groups exemplify different types of goal orientation such as:

1. Sociability--enjoyment of mutual fellowship where group activities are very informal or mainly a vehicle for communion and interpersonal relationships among members.
2. Pleasure in the performance--recreational or hobby group where the members receive satisfaction from participating in some game, hobby or sport.
3. Spectator--enjoyment through mutual exposure to some event, activity, media presentation.[30]

Ideological or symbolic. These functions represent fairly specific and elaborate sacred beliefs, special values and belief-affirming doctrines that may be highly ritualized. Religion, politics, and health are examples of such ideologies.

Self-help. The nature of these functions may be self-liberating which focus on some social problem or situation such as racism, sexism

and stereotyping. They may be self-remedying which focus on an individual problem such as drug addiction; or, self-improving which focuses on members becoming better or developing more skills but not starting with a real problem.[31] Service orientation and private interest are two other self-help functions worth mentioning. Service oriented functions are those primarily concerned with helping others, especially the disadvantaged, or society in general such as public interest concerns. Private interest functions focus on economic gain of usually already wealthy individuals and assisting private individuals in attaining some high social status.

There are a number of technical aspects of voluntary organizations that can influence their functions:

1. Goal multiplicity--one primary goal or many primary goals.
2. Goal clarity--clearly defined, precise, vague, or relatively undefined goals.
3. Goal type--political, educational, religious, health, welfare, scientific, economics, mass media.
4. Goal congruence--groups that practice what they preach or groups that specify certain goals but do something else.[32]

The degree to which any one or any combination of the foregoing elements are present within an organization will have a direct bearing on its functions.

Structures and Functions of Voluntary Self-Help Organizations

A number of groups of individuals, usually those with some sort of stigmatizing condition, not willing to accept society's traditional view of them nor the social service delivery system have organized into self-help groups. These groups seek alternatives to the bureaucratic and professional model to human services, to abstract principles, impersonal detachment and hierarchical controls.[33] The Blau-Scott typology of complex organizations utilizing "cui bono" suggests that groups can be typed by who their prime beneficiaries are and clearly indicates the helplessness of the client.[34]

Blau-Scott Typology of Formal Organizations

Type of Organization	Governed By	Prime Beneficiary
Business	Owner	Owner
Commonwealth	Voter	Voter
Mutual Benefit	Member	Member
Human Service	Community	Client

The purpose of this section is to consider some of the specific organizational characteristics of self-help groups as a basis for understanding parent groups of handicapped children. "They [self-help organizations] may best be viewed as sharing in the general purposes and functions of other voluntary health and welfare agencies, but [also] as having some particular functions and characteristics that grow out of their origin and continuing character as self-help associations."[35] In order to evolve practical strategies of participation and organizations for parents of handicapped children it is important to first look at some of the variables that characterize self-help groups.

There are at least nine structural characteristics that can be denoted as common to most self-help groups.[36]

1. Members of the group are primarily peers. They come together out of commonality of needs. In some instances this peer grouping is referred to as "minority" membership since the individuals and/or society view them as minorities because of the nature of their particular problems. There may be some professional members who are not peers but this is not a focal issue. If anything, professional membership is kept rather low-key. Professionals seem to be used not on their own terms but according to the specification of the larger peer membership.
2. The size of the group is relatively small. The membership is usually less than one hundred and often consists of only ten to twenty individuals. Peers who come together do so because they have needs that cannot be met individually and turn to a group for satisfaction. The smallness and personalization of the group are important at least initially.
3. The groups are self-governed by peer members who view themselves or their relatives as prime beneficiaries. Leadership and power structure tends to be horizontal rather than vertical. Occasionally there may be a charismatic leader who is not a peer but has some intrinsic motivation and identity with peer members. The degree to which a written constitution or by-laws exists varies. Some groups prefer to remain informal and feel

that written rules tend to bureaucratize and stifle effectiveness. Sometimes groups are compelled to adopt by-laws in order to obtain tax exempt status and qualify for funds from private or public sources.

4. Helping others is an expressed medium of the group. This is a fundamental aspect which defines self-help groups. When reference is made to "self-help" in terms of groups the emphasis is on helpfulness of mutuality and cooperation.
5. Self-help groups have common goals and goal clarity tends to be well defined. Goals emerge from within the group rather than being applied or dictated from another source. Goal orientation is toward the perceived central problem.
6. Action is group action. The group views itself as a whole greater than the sum of its parts.
7. Budgets for self-help groups are usually small in comparison to other groups. In one study the majority of budgets were less than $5,000 despite a national social service budget of $206 billion in 1970.[37] The groups have minimal staff members with most of the work being done by members.
8. The longevity or survival rate of the groups vary. They appear to be rather fragile for especially low income groups. Low income groups are less likely than groups from other social classes to have the resources such as organizational skills, contacts with influentials, access to money to keep them alive.
9. Self-help groups have frequent meetings. They meet at least monthly and some as often as weekly. This contrasts with

traditional human service organizations who usually have annual membership meetings.

These structural characteristics define the general functional aspects of self-help groups. By the nature of the concept of self-help these groups function as expressive, instrumental or instrumental-expressive. This means that some self-help groups are internally focused, others externally focused, and still others combine internal and external focuses. Self-liberating groups may center around social problems such as racism, poverty or sexism. Self-remedying groups may focus on individual problems such as drug addiction, obeseness or alcoholism. Groups combining the two foci will attempt to change the individual's self-image and society's view concurrently.

Self-help groups are action oriented in that their primary goal or goals are to produce change either among the members, within society, or both. There is a great deal of personal involvement. Members are expected to involve themselves and work for the benefit of the group. While the key motivation for participation may be self-improvement, group goals come first and self-improvement evolves as a result of working toward group objectives. This does not exclude expressive functions. As members work for group goals they have opportunities for emoting feelings and receiving reinforcement and support from their peers. However, this is the point where some groups encounter splintering or splits within the membership. Some individuals may feel the need to be more expressive or more instrumental and break into subgroups to meet these specific needs. Communication is horizontal rather than vertical and members tend to maintain close contact with one another.

In regard to functions of self-help groups "it is clear that a large number of people are being delivered a service by their peers which parallels, complements, and in many cases competes with the delivery system of the social welfare 'establishment;' and that there is a strong tendency toward 'de-bureaucratization' of this delivery system."[38]

The organizational aspects of voluntary associations are crucial to understanding participatory democracy and what variables make a difference when dealing with voluntary groups. This section has provided an introduction to the nature of voluntary organizations, reviewed three typologies, given an overview of general structural and functional characteristics, and, provided some specific features of self-help groups.

This section was prepared by Beverly Melugin.

Parents vs. the Schools

After having reviewed the concept of participatory democracy and taken a look at voluntary organizations as a vehicle for participation, focus is now turned to a specific policy area--education--and the attempts of parents to have a say in the determination of educational policy.

Parents of school-age children comprise, by and large, an aggregate of individuals who share some common concerns about the type and quality of available education. Acting either alone or in groups, they have frequently sought to be involved in and to influence decisions relating to educational programs and curriculum; school policies; regulations and personnel; where, whether and with whom their children attend school; and, even, if their children are entitled to educational services. The desire for participation in this kind of educational decision making often has implications which go far beyond the client's immediate school environment: it is bound up with the desire for self-determination of one's own destiny. A tremendously high value is placed on education, and it is seen, by many parents, as being of paramount importance for an individual's chances for future success and happiness.

However, much of the literature on the efforts of parents to participate in school-related decisions presents a picture of parental impotence against an overwhelming array of official school impermeability. One writer feels that probably ninety-five percent of parents do not ever get involved, as they are thoroughly intimidated by the mystique

of school administrators' expert knowledge. When a local group of parents does decide to campaign about something they feel is important, they are not likely to be successful. If they do manage to get a hearing, the administration generally lets them know that they are really not "qualified to comment" on professional matters.[39]

This is not to say that parents' demands are considered to be inconsequential. Parents are regarded as a distinct source of pressure on the educational establishment, and such pressure is often viewed as a threat. While school systems are encouraged to establish vehicles by which parents may express their concerns, this must be done "...in such a way that they will not constitute pressures for the educational decision makers...."[40] The decision makers distinctly do not include parents.

A school administrator, in cautioning teachers to pay close attention to parents, warns that dissatisfied parents could create pressure groups, which he regards as cancers.[41]

One study of the authority system which operates in schools indicates how and why the phenomenon of suspicion towards parent involvement is perpetuated. Teachers and administrators see themselves as professionals with specialized training, experience and knowledge in their field. Parents, lacking such a background, are felt to have no right to interfere with the work of the school. At the same time, however, school personnel recognize parents' legitimate, latent authority concerning the welfare of their children which could become mobilized, and they fear any intrusion into their sphere of influence in the school. The result is that schools have sought to prevent parents from gaining

a place of authority in the system. The schools employ strategies such as never admitting to parents the mistakes of school personnel, and principals consistently act to back up teachers and strengthen their position vis-a-vis parents.[42]

Data collected on parental grievances toward the schools showed that while about forty percent of a sample of parents had complaints, relatively few had taken action concerning them, and an even smaller number had ever banded together with other parents to seek redress. The reason that so few parents took corporate action, the study goes on to point out, may lie in the fact that individuals' grievances often do not affect other parents and groups, or that parents are ignorant of the extent to which their grievance is shared by others. That no organization exists for channeling and handling grievances may be another explanation.[43] A different writer reinforces these ideas: "...[I]t is the extreme heterogeneity of parental interests which blocks the emergence of issues concerning the school...."[44]

That parents have so often been powerless to affect educational changes in a society which claims to have local control of education has been a subject of research. In addition to within-school mechanisms for protecting and insulating teachers from parental interference, the selection and activities of school boards is, in most places, handled in such a way that the board is dominated and controlled by the superintendent. There are many reasons for this, ranging from the nonpartisan nature of school board elections to the reliance on the professional expertise of the superintendent. Board members are generally not

equipped to handle conflict and rely on the superintendent's knowledge when issues arise. But only if there is major community-wide crisis does the board respond to pressure, and then usually its action consists of firing the superintendent. Concerned groups of citizens find they have difficulty getting a hearing before the school board, as both board members and superintendent wish to avoid conflict.[45]

In the last few years, however, more and more moves toward citizen participation in school affairs have begun. A number of factors have been instrumental in precipitating this trend, among them the popularity of some widely read works of educational criticism, such as Silberman's Crisis in the Classroom and Kozol's Death at an Early Age. These books exposed school failures, exploded educational myths, and offered possible alternative models, all in language and style thoroughly readable.

But, perhaps most notable as factors leading to more parent involvement, were the civil rights movement and the anti-poverty programs of the 1960's, both of which paved the way for the occurrence of community control of schools.[46] While the civil rights movement helped to stimulate the desire for self-determination and bring about a growing dissatisfaction with the quality of minority groups' education, the anti-poverty programs provided built-in specifications for citizen involvement. Compensatory education, Head Start and other federally funded education programs encouraged and often required parent participation in educational decision making.[47]

That there was great intensity of feeling over community control of schools was not surprising. Schools had become a focal point for

dissatisfied communities of blacks and Puerto Ricans. The school was an institution that, above all, had failed them, which had been unresponsive and insensitive to their needs.[48] The schools were guilty of stereotyping children from these communities, denying their abilities, imposing curricula which were inappropriate and not providing the learning experiences necessary for success.[49] Children left schools unprepared and lacking competencies.[50]

On the part of blacks, a great deal of the intensity of feeling regarding the schools came from a belief that control of the schools meant coming a step closer to control of destiny for the race,[51] and the beginning of political potency. Community control of schools was seen as helping people who had heretofore been effectively disenfranchised from participating in society find a way toward being a part.[52]

As battles for control were fought and won--and lost--and as some schools began to be freed of a distant, unresponsive administrative structure, parents and other people in the community became involved in the operation of the schools and their attitudes changed. Whereas before the "inability of parents to have any meaningful influence in modifying...school policies" had led to frustration and hostility, there were now much more favorable and positive attitudes toward education.[53]

Consumerism and accountability, manifesting itself in lawsuits being brought by parents for failure of the schools to educate children,[54] are further phenomena causing parents to be more aware of becoming involved in shaping educational policy. Alternative schools, free schools, community schools are experimenting with parent-initiated

and parent-involved programs. New parent advisory councils have been started in thousands of school districts, and there are several neighborhood citizens groups attempting to influence school policies and practices in nearly every city.[55]

Whether parents will actually share in the decision-making process in many of the new groups which have been formed is yet to be answered, but the expression of concern and the willingness to become involved are necessary first steps to participatory democracy.

> In a nation in which citizen participation and volunteerism have been dominant themes from its beginning, giving people more influence over institutions that affect their lives has positive psychological, social and political values. Meaningful citizen involvement in decision-making can strengthen confidence in and commitment to the school, while making schools more responsible to citizens' diverse concerns. Citizen influence in educational decision-making taps new ideas and energy, and provides leverage to bring about reform in improving the quality of services.[56]

This section was prepared by Peggy Larson.

CHAPTER III

EDUCATION FOR THE HANDICAPPED: TRENDS AND ISSUES

The Nature of Special Education

To assist in understanding the complexities that must be faced by parents of handicapped children, a brief background of special education follows.

Individuals with handicapping conditions often require what is known as "special education." Special education, as a term, denotes educational practices which differ from the general curriculum to the extent of providing experiences to help cope with, overcome or compensate for the particular handicap the individual experiences.

A blind student receives special education when mobility training or instruction in braille is provided. Deaf students may learn speech reading, and captioned films may be shown for their instruction. Mildly mentally retarded students make use of high interest, low vocabulary readers. Emotionally disturbed children often participate in educational programs designed specifically to reduce their frustrations and feelings of failure. Students with perceptual problems associated with learning disabilities require special exercise in hand and eye coordination. Physical therapy is provided for children who are crippled or orthopedically handicapped. Many times two or more handicapping conditions are present. Children with cerebral palsy may have severe speech problems; the learning disabled child may also be emotionally disturbed.

Special education, as a profession, has sought to develop programs which address the educational needs of their kinds of individuals.

Additionally, there are some other aspects of special education which are significant in describing its nature.

Children with handicaps need to be identified at as early an age as possible, and programs begun to help ameliorate the handicapping condition. Programs begun at age two and a half for a deaf child can result in successful school entry into a regular classroom at age six. Preschool experiences for the physically handicapped are tremendously important in helping these children develop some mastery of their environment. Moderately and severely mentally retarded children need to learn self-care skills--dressing, toilet training--before school entry age. Preschool education takes many burdens off of parents, besides offering skill training to the child.

Equally important for some types of handicapping conditions is the provision of continuing educational services beyond those which normally cease as part of the regular school program. Mentally retarded students often require a longer time to learn skills necessary to survive. For some, community residential facilities with educational programs are needed for a lifetime.

Another characteristic of special education is the necessity for precise diagnosis of handicapping condition and educational needs related to the handicapping condition. Diagnostic evaluations must often be, and in fact in many states are required to be, a comprehensive process consisting of medical, psychological, social and educational assessments.

Individualized instructional plans or individually tailored programs are a further requirement. The particular instruction which the handicapped child receives must be based on the child's diagnosis rather than a grade-age level standard. While it is general practice to provide many mentally retarded children with essentially the same educational program, most children with other handicaps progress best with carefully planned individual programs which address their particular learning needs. A continual reevaluation of those needs is called for as well, with program modifications provided when needs indicate.

Special education, because of these requirements, is much more costly than regular education. Special materials and equipment purchases are necessary, teachers require additional training, diagnostic centers must be staffed, a lower teacher-pupil ratio is mandatory, preschool and postschool facilities need to be provided. On the average, it costs at least twice as much to educate a handicapped child as it does a non-handicapped youngster. For this reason, special education costs are a major concern.

Another concern of special education is that handicapped children be able to participate in as close to a normal environment as possible. Segregating handicapped children from the rest of the school population removes the possibility of valuable learning experiences for all children. Some instruction may best be provided in a class which is homogeneous, but the opportunity to participate in other settings is necessary for developing broader skills and understanding.

A third concern arising out of the nature of special education is the use of labels to describe various handicapping conditions. To know

that a child is "emotionally disturbed" or "mildly retarded" in and of itself does not automatically indicate the kind of educational needs the child has. In a sense, the designation is worthless. Labeling a child as "disabled," "slow learner" or any one of a dozen terms used in schools throughout the country can prove to be psychologically and socially damaging, can stigmatize the individual and predestine his or her future opportunities. A label connotes limitations on the individual's abilities.

Abuses

While the profession of special education attempts to find solutions to its own technical and logistical problems, something like four million mentally and physically handicapped children are not receiving the special education services they need and about a half million are receiving no education at all.[1] Many of the children are in regular classes or are at home because there are no appropriate programs offered in the school district in which they reside; many children are suspended indefinitely because there are no trained personnel to cope with problems that some children manifest.[2]

There are provisions in nearly all states to legally exclude some children from attending school. A child can be legally excluded when it is determined that school attendance would endanger his or her health, or the health of others, or when the child's behavior is considered to be detrimental to the welfare of other children. In many states children can be excluded when they are described as being unable to profit from school experience. Wide interpretations are possible, and no provisions

exist in many areas for seeing that alternative education be available to the excluded child. Extra legal and illegal exclusions--indefinite and continuous suspensions, waiting lists, school encouraged non-attendance, the creation of an atmosphere so punishing that nonattendance becomes the only way the child can avoid an intolerable situation--further function to deny education to children in many states.[3, 4]

Misplacement of children into special education programs on the basis of inadequate or arbitrary diagnosis is another cause for alarm. Children placed in inappropriate programs may remain there for years when no safeguards are provided for review, reevaluation and reassignment. School classification procedures often operate "to perpetuate and confirm racial, sex and class distinctions,"[5] and special education classes become a catch-all for bothersome children.[6]

There is also increasing dissatisfaction regarding the lack of educational programs and protection of rights of handicapped individuals residing in institutions. The denial of education and services to this population has recently become a focus of concern.[7]

Responses

The Council for Exceptional Children, a professional organization of special educators, has responded with the policy that:

> The provision of universal education of children in a democratic society has been translated as a commitment to the providing of educational opportunities for every child.... Children with problems have frequently been demitted from schools on the dubious grounds that they were uneducable, had undesirable characteristics or disrupted the education of other children....Since no child's right to an education may be legally abrogated, to the exclusion of any child on the ground that no facilities are available...cannot be tolerated.[8]

CEC has taken an advocacy stance, providing technical assistance in dozens of states to individuals, parent organizations and school personnel seeking to remedy abuses to handicapped children.

The Bureau of Education for the Handicapped within the U. S. Office of Education, responsible for the administration of most federal monies spent for handicapped children's educational programs, has responded by vigorous leadership,[9] including funding a national center where parents can receive information on services in their own state, and practical guidelines on their children's rights.

But perhaps most important in seeking to remedy present abuses is litigation brought by organizations of parents of the handicapped. In 1971 the Pennsylvania Association of Retarded Children, representing fourteen mentally retarded children, successfully brought suit against the state for failure to provide access to free public education. A similar case in Washington, D. C. led to the judgment that every school age child must be provided "...a free and suitable publicly-supported education regardless of the degree of the child's mental, physical and emotional disability or impairment."[10] There are presently at least a dozen class action suits which have been decided or are pending, dealing with the right to education, appropriate services and placement.

As a result of litigation, or in an attempt to avoid court-ordered changes, some states have revised their special education statuses, removing some or all of the exclusion clauses, and have begun devising new means of financing the required programs. Due process provisions to

protect the rights of parents and children have been written into official practices in states where no such procedures have been previously required.[11]

This section was prepared by Peggy Larson.

Oregon Legislation and Status

There were some 57,000 exceptional children in the state of Oregon during 1973-74 and approximately 32,000 were being provided educational services according to the State Department of Education.[12] These educational services are basically provided through five legislative acts: the Handicapped Children statute, the Mentally Retarded Law, the Emotionally Handicapped Children Law, the Children's Mental Health Services Law and the Trainable Mentally Retarded Law. The first three are administered by the Department of Education, the fourth by Children's Services Division and the fifth by the Mental Health Division. There appears to be little attempt to interrelate these programs. Each involves a different method of funding which results in some categories of handicaps being served more adequately than others.

The Mental Health Division and the Department of Education seem to have two distinctly different philosophies of program development for educational services for handicapped children, while the Children's Services Division lies somewhere in between. The Mental Health Division tends to move more rapidly in establishing programs and then works to ensure quality. The Department of Education is very methodical in its approach, spending a great deal of time documenting needs, developing well-defined guidelines and extensive curricula before moving to implementation. This was the case with the Trainable Mentally Retarded Program and partially explains why it is being administered by the Mental Health Division. Parents of TMR children, along with some professionals, had been energetically promoting and demonstrating the need for educational services for this group of children. The Department of Education

was reluctant to accept responsibility for the program and parents were unwilling to wait an indefinite length of time for services, so the Mental Health Division stepped in and developed the program. Today the TMR Program is recognized as the best special education program in the state among parents, professionals and many community members. Although there is merit in doing comprehensive program development, it should not be carried to the point of causing unnecessary delay in delivering services to children.

Prior to October 5, 1973, school-age children could be denied educational services if a child was certified physically or mentally unable to attend school or if further attendance would be educationally unprofitable for the child.[13] Further, the determination to exclude a child could be made by a district school board without consulting the parents or legal guardian. On this date House Bill 2444 became law. This law requires:

1. Local school districts to provide education to every school-age child regardless of his or her condition in life.
2. Local school districts to provide home, hospital, institutional or other regularly scheduled and suitable instruction for children who have been determined unable to attend school and are not currently being educationally served by some other regional or state facility.
3. Administrative officers of school districts to consult with parents before a child is placed in a program of Special Education.

4. District school boards to conduct surveys of the educational and other needs of children who are not attending school and report the results to the State Department of Education by July 1, 1974.

5. If necessary, that the Department of Education propose appropriate legislation to insure that the educational needs of all children are met.

A later Attorney General's Opinion on the law in reference to children who are unable to attend school states:

> [1] ...it is plain that the obligation of the "public schools" is not contingent upon the availability of any state program outlined in the statutes.
>
> [2] The school district may itself provide "home, hospital, institutional or other regularly scheduled and suitable instruction";
>
> [3] if it [the school district] does not or cannot, [provide suitable instruction] it cannot escape the obligation imposed [on it] by ORS 339.030(4), and
>
> [4] must pay the tuition of the child in an institution [private school] which does provide such instruction if that is the only way such instruction can be provided for the child.
>
> [5] There is no "out" for the school district; it must meet its obligation to the child under the statute as amended.[14]

The ruling also authorizes local school districts to pay private tuition with no financial limitation if the district does not have an instruction program of its own. School districts had previously been prohibited from paying tuition to private schools.

House Bill 2444 is a direct result of local and state parent groups of handicapped children taking action so that their children would be provided their constitutional right to educational services. This was

not an easy task. A lot of time, energy and money was involved. Many hours were spent educating legislators about the special needs and rights of handicapped children. Parents bore the expense of taking time off from work and traveling to the state capitol to give testimony. They met strong opposition from the school board association whose primary concern about the bill was raising the funds to provide the services being requested. In its final form, the bill only provided the right to "access" to an education for handicapped children and not the right to an "appropriate" education as parents had wanted. Nevertheless, one more battle in their struggle had been won.

This new law seems to have had only a mild effect to date. Although it became effective October 5, 1973, there were handicapped children in the state not being served according to the survey that was done by local school districts during the spring of 1974. This reinforces the fact that merely passing a law does not necessarily mean that children will be served. There are several problems involved. First, attitudes toward serving handicapped children vary among school board members and administrators across the state. Some still believe that certain children do not benefit from educational services because of their particular limitations, and others are concerned about financial cost and not willing to consider yet the possibility of reordering priorities. Second, HB2444 did not include a time table for serving all children nor any enforcement procedures. Third, since there was no deadline for meeting the educational needs of all handicapped children and no enforcement procedures in the law itself, administrative rules to cover these

two areas needed to be developed. However, the DOE who had the option to write these procedures has not done so.

The burden is once again placed upon the parents. If a child is being excluded or the parents do not agree after consultation with the placement of their child in a certain program of special education and they cannot resolve the issue at the local level, they have two recourses. First, they can appeal to the Superintendent of Public Instruction who may or may not work with the local district on resolving the problem. Even so, without enforcement rules, the Superintendent cannot compel the local district to comply with the law. The second alternative is for the parents to approach the courts for compliance.

Looking ahead at trends in special education for Oregon, a significant piece of legislation has been drafted by a task force appointed by the Oregon Board of Education. Two documents have been provided by this group: a proposed bill[15] which makes substantial changes in the special education statutes, and proposed administrative rules[16] with which to implement the bill. The bill consolidates all programs for handicapped children into one statute. It allows declaration of eligibility for special education and service, rather than requiring certification that a child is handicapped which would reduce some of the negative effects of labeling. The bill provides the same advantages for the institutionalized and noninstitutionalized child. It also calls for a systematic method of funding.

The proposed administrative rules make provision for due process procedures in the placement of children in special education program. Whenever administrative officers of a school district propose to place

a child in a special education program, transfer a child to or from a program, or deny a child placement in a program, parents must give their consent. If parents do not agree a due process hearing may be requested. One foreseeable problem with the due process procedure is that the appeal may be heard by the local school board or its appointee. It is conceivable that the school board's appointee could be the special education director, in which case it would be reasonable to assume that he or she might represent a biased position since this individual would have probably been involved in making the original decision for placement.

Another weakness of the administrative rules is that there is no enforcement procedure that penalizes school districts for not providing special education services. The only recourse for parents would again be through the courts if a child was being denied services. A possible means of avoiding this situation would be to include an enforcement procedure whereby basic state financial support would be withheld from a local school district if it refused services to a child. This alternative for enforcement would be a politically hot issue, if suggested, in view of the fact that the idea of "local control" of schools is widely held and supported among many school administrators and school board members. Parent groups are likely to suggest a strong enforcement procedure such as this and other changes once the bill is introduced to the Legislature.

Further trends in Oregon focus on providing preschools, activity centers and sheltered workshops for developmentally disabled and other impaired individuals. There is beginning to be a push for early

identification and training of infants through school-age children who have disabilities. Activity centers are being established to provide continued educational services to adolescents and young adults. Sheltered workshops are being set up to provide vocational opportunities for individuals who cannot function in a conventional work setting. Parent groups are working hard for services in these three areas and they are receiving support from the Mental Health Division.

Ideally, Oregon needs a system whereby educational services can be provided to all handicapped individuals from infancy through adulthood. To obtain such a system will require the continued participation of organized parent groups working as political forces.

This section was prepared by Beverly Melugin.

CHAPTER IV

PARENTS OF THE HANDICAPPED

Historical Background

Groups of parents seeking to effect changes for their handicapped children are a relatively new phenomenon, having mostly begun in the years following World War II. Several factors, as well as the war itself, had a bearing on the formation of parent organizations.[1]

The presence of a handicapping condition had been regarded for many years with a great deal of fear, guilt and general moral uneasiness. A handicapped child was often viewed as an indication of parental failing or punishment for sin, and most handicapped persons were kept out of sight. In keeping with the prevalent attitude, education of the handicapped, if it took place at all, occurred also out of sight of society. From about the mid-1800's until after the turn of the century, any educational efforts undertaken were in residential institutions.

With the growth of cities and the concomitant relatively high concentrations of handicapped children, the benefits of providing day classes within the child's own community began to be seen, and during the first two decades of the twentieth century, several hundred private day schools for the handicapped opened. Progressive education movements in the 1920's and 1930's spurred the development of classes for handicapped children in the public schools, but in most cases, teachers, administrators and the general public were not prepared, either

professionally or emotionally, to accept this move, and many classes were terminated after a few experimental years.

At the close of World War II, thousands of veterans returned home with physical and psychological handicaps. Their disabilities were seen for what they were, without the traditional stigma. The acceptance and readjustment into daily life of these handicapped persons helped to decrease the stereotyped social attitudes concerning other handicaps as well. Society in general began to achieve greater understanding and tolerance for the handicapped.

Developments and breakthroughs in the field of medicine were beginning to produce new forms of treatment. Psychological research was resulting in advances in learning theory regarding individual differences. New techniques of testing and diagnosing handicapping conditions were coming into use, making it possible to differentiate more accurately between various disorders, and allow children with the same learning needs to be grouped together for instruction. As post-war teacher training received emphasis, training for special education teachers was also stimulated and recent advances were translated into educational practices.

Prior to the war, parents, especially of mentally retarded and epileptic children, had been reluctant to acknowledge the presence of such handicaps in their families. The stigma of mental deficiency had been too vicious to discuss openly.[2] But with the shift in attitudes and the hope aroused by scientific research, parents became encouraged to come together to help make circumstances better for their children.

An ad run in the New York Times in 1945 by the parent of a cerebral palsy child, asking if there were other such parents who would like to meet together, began one of the first self-organized parent groups, which later grew to be United Cerebral Palsy.[3] In 1948 a similar advertisement brought 200 parents of mentally retarded children together. Descriptions of the first public meeting of this group portray it as having had "some of the character of a revival meeting, with parents rising emotionally to discuss their own experiences and problems."[4]

Similar groups evolved in much the same way across the country, concerning themselves with the particular handicapping condition of their children. Some of these groups, like the League for Emotionally Distrubed Children in New York, began as a result of their children being treated at the same clinic.[5] Many groups were stimulated by professionals or arose out of an agency program.[6]

The purposes for organizing seem to have been more or less consistent in all the groups. Generally, these have been: discussion of mutual problems; self-education; promoting public awareness; organizing or promoting projects to meet unmet needs of particular children; securing the passage of appropriate legislation; establishing public programs for handicapped children.[7]

Over the last two decades, groups of parents of the handicapped have raised money to support research efforts, to set up activity centers, to fund summer camps, to start recreation programs. The groups have provided transportation for handicapped children, counseling services for family members, and tuition for special schools. They have awarded

grants and scholarships to help train teachers. They have stimulated the development and provision of diagnostic centers, treatment centers, community homes. Where no classes existed, they have set up classrooms and hired staff.

With increasing emphasis on the right to education for all children, parent groups began actively putting pressure on legislatures and lobbying in behalf of public education for handicapped children. It was because of activities of groups such as the Association of Retarded Children that in state after state classes for the mentally retarded were included as part of the public school offering.[8] The Association had "remarkable influence in state legislatures, local school boards, on Congress" and parent influence is cited as responsible for many of the federally funded programs of research and training in mental retardation.[9]

When school systems have been unresponsive to pleas for change, parents have turned to the courts.[10] Litigation to achieve civil and educational rights brought by parent groups has so far been successful. Groups have undertaken vast public education campaigns to focus attention on the problems of the handicapped, and have been actively involved in assisting state and local education agencies in planning programs of services.

In some areas, parent organizations have found that, in spite of passage of bills designed to ensure services to handicapped children, the legislation was not being implemented and children were being denied legal rights. As a result, coalitions of parent groups have formed.

These coalitions, such as the Co-ordinating Council for Handicapped Children in Chicago, embrace a number of parent and professional groups, and allow differing groups to present a united front to school officials and legislatures. Among the Co-ordinating Council's publications are booklets specifying the rights of handicapped children, provisions in the laws, both state and federal, and services and benefits available. Lest there be any misconceptions of their stand, the Council also publishes a hard-hitting guidebook of practical militancy, How to Organize an Effective Parent Group and Move Bureaucracies.

It is interesting to note that parents interested in furthering the welfare of their handicapped children have organized on an international level. There are voluntary associations of parents in at least three dozen countries, and ten or so international organizations exist to share and coordinate information and activities, and help promote research and services. In developing countries where mental retardation is still regarded as a curiosity, parent groups have yet to be formed. Likewise, parent organizations, "...which function in our society as self-help organizations or pressure groups, appear to have no place in the Soviet scheme of things, where a paternalistic government is supposed to minister to the needs of its citizenry."[11]

General Characteristics

A review of the studies done on parent groups of the handicapped reveal some general characteristics which seem to be shared by all of the groups.

Observers have frequently commented on the groups' role in providing emotional outlets and in filling emotional needs for its members. Meetings of groups have been compared to gatherings of the Alcoholics Anonymous, where members spontaneously voice their feelings, frustrations and fears.[12] The provision of mutual support and a chance for release of anxieties are very important aspects of the group. The opportunity to discuss feelings with other parents who share the same problems is a continuing group function.[13]

Education of its membership has been vigorously promoted by parent groups of the handicapped. The groups sponsor lectures by professionals, hold discussions, provide counseling and collect materials on topics related to handicapped children. Training sessions may include information on the causes of mental deficiency, an introduction to the concept of psychological testing, emotional needs of preschool children or new drug therapy techniques. Parents are encouraged to make use of materials and are often able "...to discuss their reading with informed persons, since such persons are usually in attendance at their meetings."[14] Because of such activities, parents of handicapped children have been described as "...an unusually well-informed group....They are asking educators intelligent questions about the improvement of special education programs....They are a vital and importance force in the community, and they are in a position to assist realistically and appropriately in the establishment of good public school programs and to improve those already in operation. The focus of parent interest has been turned onto every facet of the problems of

exceptionality...medical research, psychological research, legislation, teacher education, transportation, finance, community health...."[15]

The inclusion of professionals and other non-parent members in the parent organization has also been of interest to many observers. While some groups sought professional members from the beginning, others began by limiting their membership strictly to parents. It became evident, however, as the groups grew and took on more functions, that the organization needed the aid and expertise that professionals could provide. The administration of larger groups became so complex and technical that it demanded "someone with professional training and skills to adequately deal with the responsibilities involved."[16] Including professionals in the membership was also in part a strategic move, resulting in firmer alliances of people who shared many of the same concerns. In numerous instances the complementary roles of parents and professionals made group efforts singularly effective, with professionals providing the expert information and parents appealing emotionally for the handicapped.[17] The disruption of this balance, as manifested by dominance by professionals, has, however, been of continuing concern to the groups. The inclusion of other "interested" citizens was usually an attempt to gain visibility, to increase the group's size, prestige or treasury, and, in some cases, to inject objectivity to the group's orientation.[18]

Levels of participation of group members have also been studied.[19] The findings indicate that only a minor percentage of parents who join the organizations become active participants. Upon first joining the groups, parents participated actively, but the majority gave less and

less of their time as goals were reached and the organization became larger and more professional. However, it was noted that parent groups were nevertheless characterized by a "quality of intensity and self-absorption" which seemed "to be one of the distinguishing marks of participation in the parent groups as compared with other voluntary associations." Added to this is the "family nature--husbands and wives being typically involved in joint participation...", the therapeutic aspects of the group and the sense of identity with successful accomplishment of goals, all of which reinforce participation in the group.

Motivations for joining the groups centered around "doing something about the problem." This implied more than getting help for one's own child; it included helping oneself, other children and their parents, and improving the state of knowledge about and responses to handicapping conditions. Many members joined the group whose children were beyond the age that could be helped by the organization. Another motivation was also expressed: parents felt that a group democratically responsive to their needs and wishes had special significance.

Parent involvement in other community groups and activities seemed to be less prevalent as compared with active leaders of other volunteer groups. This was felt to be due to the demands of having a handicapped child at home. However, cross-affiliation was looked at only for the parent members of the groups and not for the professionals.

Finally, strategies employed by the parent organizations to meet their goals show a great deal of similarity. The groups all sought to establish relationships with other agencies serving the handicapped,

not only because agencies were instrumental in providing services, but also because agency personnel were often a main source of referral of other parents to the groups.[20] The groups relied heavily on an emotional approach in their forms of publicity: "...helpless children...martyrs to a cruel situation, which an indifferent society has done little or nothing to remedy...waifs...unable to take advantage of tax-supported treatment or education...."[21] Well thought-out strategies were presented in Segal's study of associations of parents of the mentally retarded. Leaders of these groups attempted to achieve interaction and a relationship with those in positions of influence, then used facts and information for persuasion, along with liberal amounts of constituent pressure in the form of emotional appeal.[22]

While many of their efforts were met with failure and resistance, parent groups of the handicapped seem to have been able to overcome some of the obstacles to participation in educational affairs experienced by parents lacking organization. As the civil rights movement was to accomplish by arousing minority groups to the full extent of their condition, so in the coming together and sharing of concerns did parents of the handicapped develop a group consciousness of their plight and an awareness of their combined power. Like the people striving for community control of schools, parent groups found advocates at the national level and turned to professionals for technical assistance. And in working together and effecting changes, parents found they reduced their sense of helplessness and isolation.

This chapter was prepared by Peggy Larson.

CHAPTER V

DATA COLLECTION

Methodology

A case study approach was chosen for this project. The case study framework tries to find out the intricacies of a situation, it provides the opportunity to spend time among the groups being studied. The researcher can collect evidence, ideas, acquire a feeling for the dynamics of the situation and not be bound to only one method of research. Many techniques may be used--interviews, participant observation, study of printed materials. The case study method allows exploration which can give a wholistic view of the situation: "...case studies are carried out in the field with sounds, sights and smells of the real situation hitting the researcher in the face."[1]

There is at least one major limitation in the case study approach. When doing research it is desirable to find results that can be applied to several situations. Random sampling assures that the information collected will be representative. Since random sampling is not usually the method in which groups are chosen for case studies there is the possibility that the groups are not typical. The groups may, in fact, be unique. The only thing that can be done is to take precautions when selecting the groups.

There are several advantages to the case study approach. It is recognized as the classical method for researchers who want in-depth

information since it allows many techniques of data collection and integration of these techniques.[2] By utilizing more than one case study, comparisons can be made. Drawing parallels and looking at differences can provide insight into practical application. Exploring the organizational processes of the groups can also be valuable, particularly those underneath the formal structure and which may be of a very informal and confidential nature.

The function of the case study is to develop ideas which may have broader application or serve as an analysis to help bring about social change. Case studies may be presented to portray the kinds of problems some groups have been confronted with as they entered the political arena and the methods that these particular groups have devised to deal with them.[3]

For the present study, parent groups representing four handicapping conditions (learning disabled, mentally retarded, physically handicapped, emotionally disturbed) were selected. Three criteria were used in selecting the groups to be studied:

1. The group had a minimum of ten members.
2. The group was originally organized by parents of handicapped children.
3. The group was politically active; that is, the group was engaged in efforts to define policy and influence policy decisions regarding the education of handicapped children.[4]

The groups studied were located in eight Oregon counties: Multnomah, Lane, Douglas, Coos, Curry, Klamath, Jackson and Josephine.

The demographic and political characteristics of these counties are diverse and fairly representative of the total state.

Parent groups were identified by the writers while working with a statewide survey of handicapped children being excluded from school. The writers had established trust and rapport with the groups through individual contacts, conferences, workshops and group meetings. It was felt that this prior relationship was very important in allowing the writers to receive candid answers--particularly in the area of attitudes--and to be able to sit in on discussions relating to personalities of other members and targets of political behaviors.

The main source of data collection was a partially nondirective interview with individuals who were knowledgeable about the groups' organizational processes and political activities. Key questions were asked, but members were allowed to talk without adhering to a rigid set of discussion points. This provided an opportunity for them to be expressive about feelings that might have been ignored otherwise. A copy of the interview outline is included as an appendix.

Further information was gathered by observing members at group meetings and conferences, through individual dialogue and examining materials produced by the groups such as newsletters, fact sheets and notices of meetings.

This section was prepared by Beverly Nelugin.

Synopsis of Data

Twelve politically active groups of parents of handicapped children in Oregon were studied by the writers over a four-month period in the spring and early summer of 1974. A listing of these groups, without specific identification, is included as an appendix.

A total of thirty-six individuals were interviewed, all of whom were leaders or active groups members. Twenty-eight of those interviewed were parents of handicapped children; six were professionals in the field of, or closely related to, special education; and two were concerned citizens--neither the parent of a handicapped child nor a professional in special education or an allied field.

Three of the groups had been started only within the last year or so, while four had been in existence for more than twenty years. Two of the groups have not been continuously active over the years, one group having had its charter revoked by the state organization for misuse of funds some years back.

The groups ranged in size from twenty members to a "mailing list membership" or over seventy-five. In all of the groups, the active, participating membership was generally less than twenty, and usually less than a dozen. Membership varied from one group comprised almost solely of parents to those in which nearly half the membership were professionals or non-parents. Three of the organizations have definite splinter groups associated with them.

Eight of the groups were located in communities which the members interviewed felt were isolated and lacking many educational programs,

services and facilities for the handicapped. In these communities, targets of political activities were generally the school board, director of special education, superintendent or local officials of state mental health or social services programs. Targets of political behavior for groups in urban areas were viewed as the school district and the state legislature. The groups in isolated areas drew membership from widely dispersed, rural sections of the county.

All of the groups viewed themselves as successful, having received tangible benefits as a result of their political activities.

This section was prepared by Peggy Larson.

CHAPTER VI

RECURRING ORGANIZATIONAL AND STRATEGICAL THEMES

In order to determine the elements which related to the groups' political efficacy, the study attempted to determine how the groups organized themselves for participation in the process of achieving educational policy change, and what strategies the groups employed to affect changes. However, in looking at the groups, it became evident that these two aspects were intertwined to the extent of making separation artificial: the manner in which the groups were organized had strategical implications. The following recurring themes discuss both the organizational elements of the groups studied and raise points related to strategies for the successful achievement of group goals.

Membership

The groups studied were phenomenally heterogeneous in their membership. They included parents, professionals, and general community members. The groups of parents of the mentally retarded had a number of youth members--teenagers who volunteered their services to work with mentally retarded individuals. The groups represented a cross section of socioeconomic classes, diverse educational and occupational affiliations and some ethnic minorities. They varied from influential members of the community, such as the mayor's wife, to welfare parents. Some of the parents were professionals such as physicians, pharmacists,

lawyers and teachers, while others were secretaries, loggers, businesspersons, housewives or unemployed. Fathers of younger children participated and there were several married couples, but most members were mothers of older children and adults. These characteristics contrast with other self-help groups whose members are almost entirely peers having ascriptive attributes such as the same age, sex, economic class, stigmatizing condition or ethnic background. An interest in changing the educational environment for handicapped children seemed to exist in common for all members. However, several of the groups included parents of children with handicaps which were not the ones around which the group was organized. That is, several groups for mentally retarded children included parents whose children were physically handicapped. In these cases, there seemed to be no other local group for these parents, and such children were also regarded by the schools as special education students, even though their needs differed.

Accessibility to membership was fairly open. However, it was acknowledged that there were many parents of newborn handicapped children, those who had recently been diagnosed as having problems, low-income and ethnic minority children in the community who did not belong to a group. A mother commented, "Parents who really need our group are not members. They are at home just trying to cope with their child and 'make it' themselves." One group was in the process of publishing a directory that included parent groups of various disabilities in the community plus names of parents of children with specific problems that a parent could call. Another group had asked local doctors to refer

parents they came in contact with to their organization. Lack of money for low income parents to participate was also mentioned.

There were different levels of participation among the members: (1) those who paid their dues, (2) those who attended meetings and (3) a core group who did the work. One parent decried the lack of participation and commitment of most members in her group. She felt many were "half hearted, except those with their own children, and some teachers" but suspected the motives of teachers, feeling they were "obligated" to belong. Another parent was concerned that her group was not presently motivating members to tackle problems that would bring about change. Recently formed groups had more active participation than older groups. In one such group almost all members actively participated. This was attributed to the fact that the group does not encourage membership just for the sake of belonging.

Regardless of the nature of any given group there are usually several degrees of participation. The fact that there is usually a small core group who does most of the work seems to fit the general pattern of self-help groups. The important issue in the case of parent groups of the handicapped is that membership to parents should be made as accessible as possible. This means considering economic factors such as transportation, babysitting and taking time off from work so low income parents are not excluded. Remembering that ethnic minority parents are already members of one group stigmatized by society and that having a handicapped child places a double burden on them, they should be sought out. Being conscious that, traditionally, mothers have been

primarily responsible for children, special efforts may be needed to include fathers. In more sparsely populated areas, a parent group for a specific handicapping condition may want to consider broadening its membership to include children with other handicaps.

Leadership

Top leadership positions were controlled mostly by parents. Parents felt strongly that they had the most to gain or lose and that they should be in command. Professionals seemed to support this in some of the groups, taking a "back seat" in discussions where parents were expressing their feelings. A number of professionals were parents of handicapped children themselves, and these people were generally active members of groups or leaders. Chairpersons for nine of the groups were parents while only three of these positions were held by non-parents. Ten groups were headed by women and two by men. One of the men was a father of a young school-age child and his group had formed within the last year. The type of leadership displayed by parents was of a personal nature. Parents seemed to be very dedicated, taking a personal interest in their task and giving the impression of feeling major responsibility for the group. One woman expressed a great deal of concern about establishing an effective level of involvement for both parent and non-parent members in her group.

Although most chairpositions were held by parents, governing boards, which usually consisted of a group of officers, included special education teachers, doctors and businesspersons. These boards functioned in

a horizontal rather than vertical manner making decisions concerning policy and financial matters for interim periods and then seeking approval of participating members.

Leadership positions were very accessible to parents. As one recently elected chairperson put it, "I was practically volunteered into the position and any parent who was willing to make the commitment could have been chosen." However, there were no low income parents in leadership positions. They were often described as being fearful of leadership responsibilities and uncomfortable around affluent parent leaders. Individuals usually held these positions for one year at a time and sometimes longer. The amount of experience and resourcefulness that parents brought to these positions varied. Most had some prior experience in leadership roles outside the group and several active parent leaders were affluent, well known in the community and experienced in community activities. One parent described herself as being very knowledgeable "after six years of fighting the schools." Professionals who were non-parents held key leadership positions only after establishing a strong level of trust with parents or when professional participation outweighed parents in the group.

Since there is a small group of active members, leaders tend to have a great dea. of control. The caution is to be aware of this factor so that participation is not thwarted.

Professionals' Roles

Professionals who were not parents viewed themselves differently and took different roles than parents. As described by one writer:

> The inadequate communication which frequently exists between families and school personnel is, in part, a function of the negative stereotypes of parents of retarded children which have achieved the status of prominent folk myths in the professional lore. Parents of the retarded are sometimes viewed by the professional as having little to offer in the way of relevant information regarding their child's needs, feelings, problems, and strengths. There is also a tendency to withhold information from the parent....This strategy is frequently coupled with the myth of professional omnipotence.[1]

This attitude was exemplified in the stuly by comments such as, "Parents of the mentally retarded are not leadership types," "Professionals usually take over and intimidate parents," "Parents are not at all politically active," and "Parents lack confidence around professionals." Further, "While children with disabilities pose challenges to professional people, they pose problems of infinite complexity to their families."[2] This was supported by a professional when she expressed, "Parents want to talk about their children and share their gripes." It is apparent that while professionals may acknoweldge some understanding of the complexities that parents face, their real priority is to provide themselves legitimacy and accrue change for their field of special education or special services.

Parents who were professionals were more sympathetic to other parents' needs. They understood the need for expressive emotional outlets, comfort from other parents and finding out information about their child's particular handicaps. They knew what it was like to have doctors be evasive, perhaps because there were no medical answers, or to be treated less than human because one's child was different. They knew how it felt to have one's child turned away from school because there was no program or have a teacher try to tell one about what one's

child needs. They knew because they had been down that path themselves. Professionals can empathize with parents but there is no way they can really know what it is like to have a handicapped child not having been through the experience. Parents who were professionals were also more sensitive to other parents' need to gain confidence in themselves first and then learn about leadership.

There was evidence of trade-offs between professionals and parents in terms of jobs: the professionals as a source of inside information and expertise who were called upon to help lay out strategies; the parents as a source of legitimate concern. Also present was a realization that both were after the same change goal. As one parent expressed, "When it gets into politics it gets over my head but I am confident that a professional member will take over." Conversely, of a teacher who was a member: "His hands are tied because he has to watch what he says and does."

Parents felt it was important to have enough non-parents so that challenges could be made in crisis situations. This was helpful for one group who was upset with vocational rehabilitation services at the local level. They felt that the counselors were not actively seeking to place mentally retarded students in jobs. The group arranged for an official from the state vocational rehabilitation office to attend a meeting where the local counselors were embarrassed and "tactfully attacked" by the professional membership in front of their superior for not carrying out their jobs in an effective manner. The fact that the professionals understood the workings of the state agency and could speak the same

language seemed to give parents a great deal of confidence in themselves and the professional membership.

In another situation, the county special education director was anxious to assist and accommodate parents in their efforts to establish classes and provide transportation for physically handicapped children. However, he commented to the group that because of his demands for services he was not "too" popular with the district superintendents. He seemed to be saying to parents, "I am on your side but do not push too fast for I must deal with the bureaucracy that I am part of as I go."

While the expertise of professionals is invaluable to parents they should not be allowed to intimidate, manipulate or stifle parents. If this happens there is an absence of a real sense of involvement and the concepts of self-help and participatory democracy are undermined.

Goals

Two major goals can be identified for the groups studied: (1) effecting change so that more services will be provided for handicapped children and (2) providing social-emotional support to parents. Both of these goals were clearly defined, but parents and non-parents pursued them with different degrees of enthusiasm. The first goal was accomplished by such activities as applying pressure to local school boards to establish special classes or services, initiating and supporting legislation, improving community awareness about handicapping conditions and raising money for preschools and group homes.

Several of the groups were directly responsible for educating the local community about the need for special education and bringing pressure to bear on the school board in the development of classes for educable mentally retarded, trainable mentally retarded, emotionally disturbed, physically handicapped and learning disabled children. A parent commented, "I lived at the school board for years."

One group was responsible for writing, lobbying and passing a bill to include programs for emotionally disturbed children as part of the state special education program. A parent described the situation as "the first awareness that the Oregon Legislature had of emotionally disturbed kids."

Another group utilized new legislation to approach the school board and request establishment of classes for physically handicapped children. Many of these parents had been driving over a hundred miles a day in order for their children to attend special classes.

A third group confronted the school board about providing drivers' training to educable mentally retarded students, a move which established a precedent for other communities.

A fourth group, alarmed and angered when a condemned school was reopened for special education classes, contacted state officials, assisted a community committee in gathering facts on alternative programs, presented data to the school board and were successful in transferring classes to more suitable locations.

The second goal was achieved by providing a place where parents could come together and express their feelings with others who had

similar problems, and receive information and education that would help them deal with their child's handicapping condition. The groups maintained libraries of materials, received state newsletters and national publications. Guest speakers provided information and parents attended workshops relating to specific handicapping problems. Some groups had subgroups of "parents only" to discuss personal and emotional feelings. One parent was quoted as saying that when she got help from the group in working with her child she could see "tremendous changes" in the child's behavior. Another group was producing a film on learning disabilities to be used for parent education and teacher training.

Although professionals who were not parents acknowledged the need for expressiveness, they did not share this goal with parents. An example of this is when one professional said, "There is too much emphasis on emotional aspects and not enough action." Professionals were more interested in change as related to their own field (e.g., special education, medicine, psychology). There was also goal variance among parents of children in different age groups. Parents of young children wanted preschools as a priority while parents of older children wanted employment and group homes emphasized.

Goals of the group need to be congruent; mutual agreement among parents, professionals and general members on the goal of change. Parents need professionals and general members and vice versa. In order for the organization to be an effective instrument of change, allowances must be made so parents can obtain their additional goal of expression, information and education. This must be done in a manner that does not

endanger the participation of parents. Additionally, there needs to be provisions for parents with different aged children to obtain their specific goals without diffusing the effectiveness of the group.

While there needs to be goal congruency, there should be an awareness that goals will change over a period of time. As one problem is solved another may be created. For example, passing legislation to ensure that all handicapped children have a right to education may be a group goal. Once the legislation has been passed there may be a problem of implementation. Consequently, one problem has been solved but now a new one exists. The point is that groups should understand the probability of this happening and be able to readjust their goals without sacrificing their effectiveness.

Splits

Splits were observed, most noticeably between parents of children of different ages and between parents and non-parent members. Parents of older children wanted programs to meet their children's needs, were not as interested in programs for preschool-age children, and generally did not support more "progressive" programs such as integration of handicapped children into regular classes or the concept of deinstitutionalization. Especially, mothers of older children, "who for years battled alone" to get separate classes and institutional services that would attend to the needs of their children, tended to have different views than younger parents. This difference of views is representative of how attitudes toward handicapping conditions and approaches of dealing

with them have changed. Older parents recall the excessive guilt placed on them and the almost total absence of services for their children. They worked hard to establish special schools and institutions that would provide for the needs of their children and take some of the burden off them, since society was then more tolerant of stigmatized individuals being grouped together rather than integrated into the community. Younger parents hold the philosophical view that their children should be "mainstreamed" into all aspects of society--schools, occupations, health care, recreational and legal services. This is evidenced throughout the study by their endless efforts to initiate legislation, apply pressure to school boards and service agencies and educate the public about handicapping conditions.

Non-parent members of the group tended to be impatient, to not understand and sometimes to express hostility when parents wanted to develop their own subgroups to serve as social-emotional outlets, or to deal with problems of their own children. One non-parent member expressed disappointment in parents who were "only concerned about their own children." Others expressed dissatisfaction over parents being active only when the group spoke to their child's needs. One parent who was also a professional seemed to have a good understanding of the situation when she explained, "Large group meetings where the talk is of federal grants and such just do not meet social-emotional needs of parents."

There was some internal division between parents of mildly handicapped and severely handicapped children. Mildly handicapped children

were more often served by the public schools, whereas severely handicapped children attended private schools and institutions, leading to a different focus for the parents of these two types of handicapped children.

This issue is interwoven with goals and the roles of professionals. If goals are congruent and roles of professionals are understood, splits should not necessarily have a negative, dissipating effect. A splinter group to fill certain needs can coexist within the larger group. If recognized as such, as was the case in one organization, there may be more willingness to put aside individual needs and work toward the larger group goals when action is called for.

Alliances

All groups felt they had established alliances locally with other community groups, agencies or individuals which would help further their efforts. This was done by developing and maintaining working relationships with city and county officials, mental health workers, legislators, county health personnel, developmental disabilities coordinators and intermediate district level employees. Often there were alliances with teachers where parents took the role of making presentations to school boards (which might have threatened teachers' jobs had they taken such action). Parents seemed to have better feelings about local school and agency officials once they were part of the group and everyone was working together for the same goals. One group aligned with the local teachers' association to get a sympathetic person elected to the school board.

Cross-affiliation was recognized, encouraged and used by the groups. One father, who by profession was a physician, was a member of the school board and a mother who was chairperson of one group was also a school board member. In both of these instances, being elected to the school board had been strategic moves on the part of each respective group to directly influence policy making decisions regarding programs for handicapped children. Other individuals were also active members of civic, environmental and service groups, professional organizations, unions, political parties and religious groups.

As mentioned earlier, in this paper, previous studies have found few cross-affiliations among parents. In this study, both parents and non-parents who were active and those in leadership positions were engaged in other community activities, well known, influential and, often, affluent members of the local "power structure." However, parents who were not professionals nor active in leadership roles had few cross-affiliations.

All of the groups except one were affiliated with their respective state and national organizations. Affiliation was viewed as a vehicle to influence policy decisions that would affect individuals throughout the state and country. The groups seemed to have an awareness that while they could work toward making changes at the community level, major policy was often set at the state or national level and simply implemented locally. Therefore, their grass roots work of improving service delivery, influencing interpretation of regulations and administration was only one step toward bringing about substantial change. This was

exemplified by groups that raised money locally to establish classes, group homes and activity centers to demonstrate needed services while working at the same time to get legislation passed at the state and federal level that would create public funding or ensure the rights of handicapped children to existing services. (See appendix for a review of selected national parent organizations.)

In regard to their particular state organizations the groups felt their affiliations increased their efficacy and that they could count on them for outside help and expertise. It was mentioned that the state groups provided confidence. In one situation when parents were protesting the removal of a well-liked special education director no one knew just how to go about it or even if they "had the right" to protest; the state organization provided assurance and support. Other examples were cited of the state groups assisting in applying pressure. Some groups were looking to the state groups to provide more leadership training especially to parents who have had little experience in this area.

The state and national organizations provided resources in the form of funds, information, expertise, legal aid, and sometimes legitimacy for newly formed groups. Their contributions were often psychological as well as actual.

A precaution that should be considered when forming alliances with other community groups is whether or not it offers real participation or is merely tokenism. For example, if a member of a parent group sits on the citizens advisory council for the school board representing the

parent group, that individual should have an opportunity for meaningful input.

Since the groups have aligned themselves with other groups within the community and their individual state organizations, the next logical step should be to develop coalitions of parent groups of the handicapped. They should be ideologically compatible. Goals and commitments of all groups to be involved in the coalition would need to be considered. However, once some consensus was reached there would be possibilities for a good power base and effective change not afforded single groups.

Longevity

Parent groups of the mentally retarded have been in existence for some twenty years while those of the emotionally disturbed, physically handicapped and learning disabled have been recently organized. One group specifically stated that they wanted to get the job done and get out and others hinted at it. This may be more feasible for the latter three groups than for the mentally retarded. In some instances, once medical programs, educational and social problems are designed and available, parents may not need to be such central figures in their children's lives. However, in the case of the mentally retarded and other severe types of handicapping conditions involvement of parents may be for a life span.

The length of time a group had existed had an effect on the level of participation and vitality of the group. New groups were energetic

and dynamic while older groups seemed often to be drained of energy and lacking enthusiasm.

It is not possible and probably not even desirable for a group to maintain its youth. What is important is that as the group matures it has the capability to maintain its vitality and be self-renewing.[3] This is related to the group's understanding that goals and structures change over time and its ability to make these adjustments will determine the degree to which the group can be self-renewing.

Strategies

In addition to the foregoing organizational characteristics intertwined with strategical themes, there were some particular strategies employed by the groups which should be noted or in some instances restated.

1. Emotional appeal was felt to be a viable tactic to be employed by the group in arousing sympathy to the parents' cause. One parent's emotionally disturbed teenager gave testimony at a legislative hearing. Other parents testified at school board and agency meetings describing the pain and frustration of their situations and the plight of their child.
2. Confrontation was not avoided; parent groups used this means with success in several instances. Directly challenging local officials in full view of their state level superiors brought hoped-for changes. Waging a protest against a local school district when it attempted to reduce the special education budget resulted in cuts being reinstated.

3. Gaining information and self-education was also used as a strategy. Parents had facts with which to confront the school board or community agencies when making demands for new or improved services.
4. Aligning with key groups in the community, either through making friends or by including them in their membership was mentioned many times as being of utmost importance. Also affiliating with state and national organizations was viewed as crucial in affecting policy decisions at a meaningful level.
5. Utilizing professionals to provide expertise that parents lacked, as well as to increase the strength of the group was a strategy which all but the very newest group employed.

The following short anecdote exemplifies how these strategies were often put into action.

A group of parents of learning handicapped children decided to make a proposal to the school board to provide in-service training to elementary teachers, evaluation of all children behind in school one year and the establishment of a special advisory committee made up of parents and professionals. The group carefully worked out a plan of attack before going to the school board. First, they attended two school board meetings and observed other groups making presentations to determine what worked and what turned off the school board members. The proposal was well developed and well written. Help was enlisted from a governmental proposal writer and a lawyer. Letters explaining the proposal

were sent to individual school board members prior to the presentation. The press was contacted about the proposal before the meeting. The presentation was done by a parent (to evoke emotional response), a professional (to provide expert opinion of what the outcome would be if learning disabled children were not provided special attention) and a teacher (to describe what happens in the classroom). Members of the group filled the school board meeting room on the night of the presentation and wore buttons identifying themselves and their purposes. The school board appeared shocked to learn of such a great need within their system and agreed to the proposal. The group feels that this proposal provided a cohesiveness among parents, teachers and other professionals and that the school board is now on their side. The press coverage received acted as information to increase public awareness about learning disabilities and produced a new degree of credibility for the group within the community.

The organizational and strategical elements discussed above all bear upon each other. For instance, the type of leadership whether it be parent or professional will influence the setting of goals and the strategies employed. Similarly, the composition of the membership relates to the amount of cross-affiliation present within the group. The length of time a group has been in existence will affect splits within the group and goals of the membership of the group. Likewise, the type of leadership will influence the type of members the group attracts.

For the groups studied these organizational characteristics and strategies seem to be of considerable importance to the success of the groups' endeavors. Consideration of these and similar elements would seem important to anyone working to make self-help groups viable.

This chapter was prepared by Beverly Melugin.

CHAPTER VII

SUSTAINING THEMES

In seeking to discover what factors seem to sustain involvement in the group, parents were asked about their feelings and attitudes toward their own involvement. All of these parents were leaders, and had a high level of participation. In older groups, these individuals had generally been active for a long period of time.

From an analysis of the responses, several variables emerged which were most frequently encountered as having significance for the individuals.

Accomplishments

All parents interviewed felt that the groups were making headway, achieving real changes for handicapped children as a result of their efforts.

After one group had extracted promises from state and local vocational rehabilitation counselors, they described their feeling as "very powerful." A group which had worked for over a year to establish public school facilities for their children and who were successful in their efforts seemed very encouraged to tackle more problems.

This extended not only to the active participants, but to the members who participated less actively as well. One parent said that although the same core group did most of the work, the total group had

a "beautiful high" after a successful school board presentation. "A winning team attracts players" was another comment. In another group, after a small number had worked hard to set up a community residence for the mentally retarded, nonactive members were overheard at the open house "congratulating themselves on their accomplishments."

The groups viewed themselves as fairly potent, and efficacy in terms of successes seemed to be a major factor sustaining many members' activity.

Sharing

There was a definite expression of a common bond, us-against-the world, in a number of the groups. In the newer groups there seemed to be a strong feeling of identification with other parents, which generally excluded the members who were professionals. "In the end, it's up to us." Most parents felt that this shared, common concern was psychologically very reinforcing. In several instances, both parents were active group members, which extended the feeling of sharing.

A couple of a physically handicapped child related to the group the efforts of a neighbor to have the child removed from their custody. The support and sympathy that this story aroused from other parents seemed to be extremely gratifying for the couple.

One individual expressed the feeling that in the act of simply joining the group, many parents felt they were participating.

Although the membership was extremely heterogeneous, there was an element of mutual concern which was expressed by all members interviewed.

Intellectual Stimulation

One of the most frequently expressed feelings about playing an active role in the group was that it was intellectually stimulating. Particularly for those parents who felt they were living in an isolated community, the chance to meet and interact with state officials, professionals, "out-of-town experts" and community leaders were regarded as important for sustaining their involvement. One member traveled with a group of professionals and parents on a statewide tour of exemplary special education programs and facilities, a trip which increased her enthusiasm tremendously. For another parent, the group activities awakened an interest in special education to the point of her going to work at the intermediate district office. Parents said they were stimulated by what they did in the group and by the people, both in the group and without, with whom they associated as members of the group.

The president of one group said that she was "reinforced by the stimulation of the job" even after her own child was beyond the age where the group could be helpful.

There was expression about being stimulated by learning more about the world of politics. Legislators and attorneys were brought in to address one of the groups, and the group took a lively interest in the discussions. One parent seemed fascinated by the inter-educational-establishment workings.

Additionally, learning factual information about the psychological and medical aspects of their children's handicaps was mentioned--and observed--as generating a great deal of interest.

One parent stated simply that she would become stale and bored if she stayed at home. Another parent spent several hours during and after dinner talking about the parent group to the exclusion of any other subject.

Emotional Outlets

For parents, the opportunity to express feelings and concerns was an important aspect in initially bringing them into the group. "What was of tremendous importance was the emotional outlet."

However, while recognized as such, the parents interviewed seemed to feel that they themselves had progressed beyond the point of emotional catharsis being the major sustaining force responsible for their participation. They recognized this need existing for parents, particularly for new parents and ones in more isolated areas of the county (and often, by intimation, for ones of a lower socioeconomic class). But they seemed to indicate that those parents who primarily came to meetings only to release emotional tension and talk about their own problems were not the active participators in the group.

Legitimacy

For several of the parents interviewed, their role and function as leaders or members of the group legitimized what they had been doing previous to joining the group. "I have a reputation in this community for stirring up trouble" was heard on several occasions. One parent said that now that they had a group, she had "more confidence" to face the school principal and her child's teachers. Another parent seemed to

have always viewed herself as an agitator, a provacateur, and one gets the impression she had redoubled her efforts as a result of the group's backing. A parent who previously took upon herself the role of community educator about mental retardation now has more information to dispense since her affiliation with the group.

This sense of legitimacy may be closely associated with a feeling of power, particularly the power felt by belonging to a group which has achieved successes. One parent felt that school people did not take her seriously, that she got the run-around, before the group was formed. Now, as part of the group, she feels that their attitudes toward her have changed.

Helping

The expression of being able to help as part of the group was reiterated by nearly everyone interviewed. "I feel like I'm doing something to help." "I don't want other parents to have to fight the same battles I fought." By becoming involved in the group, parents felt they were helping not only their own children, but other handicapped children as well. "It's too late for my child, but not for the others," was the feeling expressed by one fairly active member who had worked to establish a class for the physically handicapped.

Helping as a strong motivating force was brought into relief by one parent leader who explained that "many parents are fearful that if they complain or try to exert pressure, they may lose their jobs, or that agencies will take away and institutionalize their child." The problems for which help is needed are psychological in many cases.

Parent saw the group as a vehicle by which they could help their own children, other children, each other, parents who were not group members, and even professionals who shared the same goals. Parents went before the school board to press for expanded special education services, acknowledging that other members who were teachers, could not afford such a risk. Another group brought withdrawn parents into contact with school personnel for the first time and were very pleased with having been able to accomplish this. Helping seemed to be a very reinforcing factor.

Individual Development and Self-Expression

A number of parents seemed to feel that their active participation in the groups provided them opportunities for self-growth, to learn skills and to personally develop their abilities. "Parents call and ask me how to do something or how to make a presentation." One group president felt that her group involvement was more help to her in this regard than providing instrumental benefits to her child. By actively participating, parents felt they were more able personally to cope with the community and school environment. Frequently stated was, "If I only knew then what I know now...."

One couple seemed to have blossomed, becoming far more articulate as a result of belonging to the group.

Closely related to self-growth was the opportunity for self-expression that was provided by participating in the group. Successfully chairing a meeting, leading a discussion, negotiating with professionals were undertakings which enhanced active participants'

feelings about themselves. One parent talked about how her involvement did "wonders for her self-image."

Idiosyncratic Needs

Several parents expressed attitudes about their role in the groups which can be best described as filling individual or idiosyncratic needs.

One parent seemed to identify strongly with the professionals in the group, although she herself had no professional background. She seemed to be proud of the fact that she was "in it" together with professionals, working shoulder-to-shoulder, and perhaps feeling that a little of the professional aura was rubbing off on her.

Another parent was definitely reinforced by being in a position of authority. Although she expressed some concern that she had so much influence in the group that she was in almost total control, it was obvious that she had enjoyed her position.

A third parent's very active participation seemed partially to stem from needs related to a fairly recent divorce. Her almost total involvement and commitment to the group's success--both actually and psychologically--may have been an attempt to fill a void or compensate for other perceived inadequacies.

A fourth group leader--neither a special educator nor parent of a handicapped child--seemed to be using her engagement in group activities as a means of self-identity, almost protest, against a husband who was nonsupportive and a life which otherwise would revolve almost totally around the household.

The above variables appear to be significant factors for sustaining participation in politically active parent groups, as found in this study. There is a great deal of interrelatedness of the variables. Although presented separately, a number of the variables mutually reinforce each other and, by degrees, shade off into each other. It is hard to say where a sense of group identity or sharing leaves off and the feeling of legitimacy begins. Likewise, intellectual stimulation may be very close to self-expression and idiosyncratic needs only an extreme form of another variable.

It is interesting to note that, for each of the parents interviewed, several variables were mentioned as playing a role in sustaining their active involvement.

In sum, individuals need to be part of a group which is successful, with which they can identify, and which provides them with intellectual stimulation and a sense of helping and sharing. The group needs to fill some individual needs, such as emotional outlets and self-expression, and also to provide skill building and growth experiences. In addition, idiosyncratic needs must be filled in such a way that they help rather than hinder individual efforts toward group goals.

This chapter was prepared by Peggy Larson.

CHAPTER VIII

SUMMARY

This study has looked at the inner workings of politically active parent groups of handicapped children in Oregon in order to understand some of the ingredients of participatory democracy. The position was taken that it is desirable to learn more about participatory democracy because of its importance to individuals and to society. The study focused on the self-help voluntary organization, one of whose functions it is to provide individuals a structure in which to actively participate in helping to shape political decisions which affect their lives. Politically active parent groups of handicapped children were chosen as an example of such organizations because they have a history of being active and successful in achieving political changes and because there continued to be a need for such groups, given the problems and issues which still exist in education for the handicapped. Political activity for the groups studied was defined in terms of effecting changes in educational policy.

The study examined twelve parent groups of handicapped children by means of in-depth interviews with leaders and active members of the groups. Data were analyzed with respect to two considerations: organizational and strategical elements important for a unit of people engaged in participatory democracy to be effective; and attitudinal variables which motivate individuals to be politically active and

sustain their involvement within the group. Eight closely interwoven organizational and strategical characteristics of the groups were discussed as being critical areas that similar groups who wish to achieve political changes need to consider. Eight similarly interwoven attitudinal variables were identified as yielding important insights into the factors which sustain individual participation in the groups.

While these two components--political efficacy and participation--were separated out for the purposes of analysis, they work in combination within the groups. In the words of one parent: "As we joined together, we became stronger and braver and more aware of long-range needs and our capability for achieving goals."

The outcome of this study, in the view of the writers, is that participatory democracy is a possibility. The groups studied seemed to work; political activities resulted in changes. The people interviewed were both excited about their efforts and confident that what they were doing was right. There were identified some definite organizational and strategical elements which assist in the undertaking of the participatory process and some definite attitudinal variables which mobilize and sustain individual involvement.

The study, while focusing on parent groups, has identified some of the aspects of participatory democracy which should be applicable to other groups and organizations of people who strive for changes--both in their political environment and, further in their own lives and self-concept.

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APPENDICES

Interview Outline

Organization

Persons Interviewed, length of time involved

History of organization, affiliation, growth and decline

Membership characteristics (parent-to-professional ratio, leadership, active members roles, cross affiliations of members, group splits)

Goals (main purposes)

Strategies

Examples of political action efforts, with attendant feelings

Relationships with targets of political behavior

Attitudes toward participation

Comments, reflections

Materials

List of Groups Interviewed

County A

- Parents of Learning Handicapped Children
- Parents of Mentally Retarded Children

County B

- Parents of Mentally Retarded Children

County C

- Parents of Mentally Retarded Children

County D

- Parents of Physically Handicapped Children
- Parents of Mentally Retarded Children

County E

- Parents of Mentally Retarded Children

County F

- Parents of Learning Handicapped Children
- Parents of Mentally Retarded Children

County G

- Parents of Emotionally Disturbed Children
- Parents of Learning Handicapped Children

County H

- Parents of Mentally Retarded Children

Selected National Parent Organizations

To reflect a total image of how parent groups of handicapped children participate in effecting change in some national parent organizations will be reviewed. A short historical overview and some organizational characteristics of five national groups who have affiliates in Oregon will be presented: Association for Children with Learning Disabilities, Epilepsy Foundation of America, National Association for Retarded Citizens, National Society for Autistic Children and United Cerebral Palsy Association. These national groups were selected because they have recently been the most active groups at the state level seeking legislative and programatic changes.

Association for Children with Learning Disabilities

The Association for Children with Learning Disabilities originated in 1964. It was formed by parents and professionals from seven states who were involved with children with learning disabilities. Today, the membership includes some 40,000 parents and professionals in the areas of education, psychology, medicine and health. ACLD is a nonprofit organization with affiliates in forty-eight states who have local chapters.

The purpose of ACLD is to advance the education and well-being of children with specific learning disabilities of a perceptual, conceptual or coordinative nature. Specific objectives are to:

1. Increase public understanding and awareness of the nature of learning disabilities.
2. Insure early intervention and identification of learning disabilities for all school children.
3. Ensure that local educational systems provide the necessary services so that each child may reach his or her potential.

Policy is determined by ACLD officers and board of directors and guided by a professional advisory board of sixteen members from the field of learning disabilities.

ACLD estimates that seven percent of all school-aged children have a severe enough learning disability to require special intervention. Some indications of learning disabilities are classroom inattentiveness, difficulty with reading, writing, spelling, math, coordination and speech. Learning disabled children are often clumsy, awkward and may have difficulty grasping simple abstract variations of everyday life. The origin of learning disabilities is thought to be physiological with the child's brain suffering from minor tissue damage, a chemical imbalance or a maturation lag of motor and language functions. Most learning disabled children have average to above average intelligence and should not be confused with primarily retarded or primarily emotionally disturbed children. Children with learning disabilities are often thought to be stubborn, difficult discipline problems and parents are blamed for not providing firm limits.

Epilepsy Foundation of America

This group is the outcome of many years of struggle to establish a unified national organization for epilepsy. The first group concerned with epilepsy was formed in 1898 but failed after little more than a decade. Since that time, thirty or more voluntary groups tried, unsuccessfully, to work in behalf of epilepsy patients. Their failure is attributed to a lack of unity and inability to develop and implement long-term programs and activities. At that time it seemed impossible to attack the problems of epilepsy in a systematic way since there were no common research efforts, it was difficult to develop educational, vocational and training programs and the prejudice about epilepsy was overwhelming. The introduction of Dilantin, an anti-convulsant, in 1938 and the educational drives for crippled children and World War II veterans helped change the negative attitudes toward epilepsy.

Founded in 1967 after several mergers, the Epilepsy Foundation of America is now the official group working on the attack of epilepsy for some four million individuals who have disorders of the central nervous system. There are 140 affiliates throughout all fifty states. The major goals are to act as spokesperson, advocate and ombudsperson for those with epilepsy, helping them to define their problems and develop programs to help solve these problems. The Foundation has some nineteen categories involving seventy-three specific programs or activities functioning. All of these take place in three major areas: medical, social and information and referral.

The Foundation is governed by a Board of Directors made up of forty-five volunteers representing professionals, business community and consumers. There is also a fifty member Professional Advisory Board representing physicians. educators, lawyers and other professionals. There are several independent professional groups such as physicians specializing in epilepsy and research aligned with the Foundation.

The EFA publishes a monthly newsletter that is quite extensive along with numerous other booklets, pamphlets and reports relating to programs and problems of epilepsy.

National Association for Retarded Citizens

The National Association for Retarded Citizens was founded in 1950 when forty-two parents met in Minneapolis, determined to unite their efforts. They were motivated by personal sorrow, frustration and disappointment. The task ahead of them was formidable. Mistaken beliefs about mental retardation needed to be changed to knowledge and acceptance. Services were needed to provide diagnosis, education and care. The organization was first known as the National Association of Parents and Friends of the Mentally Retarded Children. By 1960 there were 750 local chapters. By 1965 the organization had changed its name to National Association for Retarded Children and had grown to be one of the most dynamic voluntary organizations in America with a membership that exceeded 100,000. Today there are some 1,500 state and local associations with 225,000 adult and 20,000 youth members. The title has also recently been changed from Retarded Children to Retarded

Citizens. This is reflective of their expanded role of services to include a life span rather than just childhood. The membership represents parents, professionals, community members, adolescents and retarded persons.

NARC views itself as having dual goals: "to ensure that mentally retarded persons share fully in all human rights and services, and, for the sake of future generations, to diligently pursue every feasible avenue in the area of prevention." Currently there are six programatic priorities:

1. Outreach--to assist in breaking the cycle of poverty with its associated harsh and frequently dangerous living conditions which contribute to the disproportionately high incidence of mental retardation among low-income groups.

2. Education and Training--to promote full educational opportunities and new approaches to education for all mentally retarded persons, regardless of age or ability level.

3. Prevention--to ensure that current available knowledge concerning the causes of mental retardation is utilized in reducing the incidence of this condition.

4. Residential Services--to encourage the establishment of small, community-based, home-like residential facilities as alternatives to institutionalization and to ensure the maintenance of quality residential training programs.

5. Rights of Retarded--to promote public awareness and mobilize citizen efforts to achieve full human and civil rights for mentally retarded individuals.

6. Habilitative Services--to achieve a comprehensive and normalized array of services intended to prepare every retarded person for a productive and useful life in the community.

The achievements of NARC over the years are numerous. Some of their most recent achievements include:

1. Research--development of screening procedures for PKU, an inborn error of metabolism; investigations on the effects of malnutrition; relationship of viral infections and association of chromosome abnormalities to specific defects.
2. Residential Services--intensive program aimed at eliminating dehumanizing conditions of private and public residential institutions and establishment of Accreditation Council of Facilities for the Mentally Retarded.
3. Employment--promoting meaningful employment at governmental and private level.
4. Citizen Advocacy--encouragement of citizens to pursue relationships with mentally retarded individuals.
5. Legislation--supported Elementary and Secondary Education Amendments of 1969; Lead-Based Paint Poisoning Prevention Act and Developmental Disabilities Act of 1970.
6. Furthering Legal Rights--ARC has initiated numerous class action suits.

NARC is the largest, most visible self-help parent organization in existence today. This is partially due to the size of the population affected by some form of mental retardation--three percent of the population or more than six million individuals in the United States. It also represents fierce determination of parents to bring about changes for their children and relieve some of their own burdens. Although it has been devoted primarily to promote the well-being of mentally retarded individuals it has picked up members representing other handicapping

conditions over the years, particularly where there was no other group for parents of children with different handicaps to join.

National Society for Autistic Children

Dr. Bernard Rimland, psychologist, author of Infantile Autism, and parent of an autistic child was responsible for establishing NSAC in late 1965. This group decided to include all children with severe disorders of communication and behavior in addition to those diagnosed "autistic." The organization has grown from only a few local and state chapters in 1966 to over 100 today. Membership is primarily parents and professionals. Community or general members are almost nonexistent in this group. Autism is a rare and little known condition with only four out of every 10,000 children being affected. NSAC defines "autistic children" as those with severe disorders of communication and behavior whose disability becomes evident in the early stages of childhood development. The "autistic child appears to suffer primarily from a pervasive impairment of his cognitive and/or perceptual functioning, the consequences of which are manifested by limited ability to understand, communicate, learn and participate in social relationships."

NSAC has a national policy which states that it will not be a direct service organization. Rather, it works to get autistic children into already existing programs in communities around the country. NSAC encourages the establishment of local chapters to push for relevant and useful school programs. It works to enact enlightened legislation for mentally ill children and has helped supoort parent-initiated lawsuits

where parents have sued for the inclusion of their children in public schools. The Society has pressed the National Institute of Mental Health to do more research in the biophysical and biochemical aspects of mental illness in children.

One of the most important functions of NSAC is information and referral. It has one of the most complete sources of information available on the mentally ill child. The group also publishes a newsletter which is directed toward helping parents with specific information on what can be done for their child and how to cope with their problems. Another means of disseminating information to parents and professionals is through the annual meeting and conference.

Members of the NSAC feel that their organization has made a difference. As a recent president of the group expressed it, "In the past we have always been a 'little giant' of an organization; now we have become a significant national force." Parents working together are feeling and exercising their power, and there is felt to be hope for many who were alone only yesterday.

United Cerebral Palsy Association

United Cerebral Palsy Association is a network of 300 state and local groups which grew out of the need for parents to come together for mutual support. It was founded in 1949 and has steadily grown since. Six years after its inception the UCP Research and Educational Foundation was established to stimulate and fund research and train personnel. By 1973, some thirteen million had been expended in foundation activities

and considerably more had been stimulated for research by governmental and private agencies. In addition to research, it establishes models of exemplary services for the handicapped, serves as an advocate in governmental activities, promotes legislation and encourages federal, state and local programs to benefit individuals with cerebral palsy. The Association assists affiliates in their local programs by helping assess needs, enlisting support and interpreting programs to the community.

There are no official figures available on the number of individuals who have cerebral palsy but UCPA estimates that as many as 750,000 are affected in some way. Cerebral palsy is a condition which results from damage to the brain. "Cerebral" refers to the brain and "palsy" to a lack of control over the body's muscles. It may inhibit an individual's ability to walk, impair hearing, sight and speech, produce mental retardation and cause seizures and spasms. Sometimes the impairment is only slight while in other instances it is quite severe with multiple handicaps.

Some groups (Association for Retarded Citizens, United Cerebral Palsy and Epilepsy Foundation) are well established at the national level. They have sizable professional staffs, carry out a number of well developed programs, and are recognized for their activities in legislation and research. These three organizations are also joining forces to plan joint programs as a result of the Developmental Disabilities Services Act. This law provides funds to serve those who have neurological handicaps originating in childhood and specifically includes mental retardation, cerebral palsy and epilepsy.

Fairly new groups (Association for Children with Learning Disabilities and Society for Autistic Children) are still very parent oriented, even at the national level. They are continuing to develop new programs and are seeking more recognition and visibility in the areas of legislation and research.

This section was prepared by Beverly Melugin.

List of Materials Reviewed

Association for Children with Learning Disabilites, "Fact Sheet," 5225 Grace Street, Pittsburg, Pa. 15236.

Epilepsy Foundation of America, "Program/EFA Activities to Help People with Epilepsy," and "History of the Epilepsy Movement in the United States," 1828 L Street, N. W., Washington, D. C. 20036.

National Association for Retarded Citizens, "Fact: One Out of Every Ten Americans Has a Mentally Retarded Person in His Family;" "Voices in Chorus;" and "Why We're Here," 420 Lexington Avenue, New York, N. Y. 10017.

National Society for Autistic Children, "A Brief History of the National Society for Autistic Children," 169 Tampa Avenue, Albany, New York 12206.

United Cerebral Palsy Associations, Inc., "Cerebral Palsy--Facts and Figures," and "What Are the Facts About Cerebral Palsy," 66 East 34th Street, New York, N. Y. 10016.

"How outraged I would be if I couldn't get into a phone booth and make a call, couldn't get on a bus, couldn't go to a rest room, couldn't get into a building," he said.

He said he had met handicapped children aged 3 or 4 "who, through some miraculous way, don't comprehend what's in store for them. So, they have a smile on their face."

But, he added, "you see the same kids several years later, in their teens, when they've begun to see what's ahead of them," and the smile is gone.

A panel of Eugene-Springfield school personnel will be held tonight during the first meeting of the Eugene Chapter of the As n. for Children with Learning Disabilities.

Autistic children

BY LAW ALL CHILDREN IN OREGON ARE ENTITLED TO FREE EDUCATIONAL SERVICES

But some are not in school A new Oregon Law, House Bill 2444 (1973), affirms the right of all school-age youngsters (up to age 21 for the handicapped) in the state to benefit from free public education.

YOU CAN HELP! JOIN OREGON PROJECT CHILDFIND.

If you know about a youngster who is not attending school, whatever the reason, help give him/her a better chance in life. Show this ad to his/her parent . . . or

If you were the parent
mentally disturbed child
Lane County, the pros-
ts of education within the
ailable system would look
eak. The mold of the pub-
ic school system might not
provide the special care re-
quired for some children.
The alternatives to public
school are facilities located
elsewhere in the state or li-
mited care in the juvenile
facility. The alternatives
are grim.

Woman seeking to organize parents with deaf children

A Junction City woman has launched an effort to create a statewide organization in Oregon for parents of deaf children.

Purpose of the group, according to Lou Campbell, would be to provide parents of the deaf with infor-

Angela Coleman, a 9-year-old partually blind girl from Augusta, Ga., is grades behind in reading because her school can't afford special books with large type.

Twenty-two educable but autistic children in the Tidewater area of Virginia were turned away from schools because the added costs of teaching them were too much for their community to bear. The parents are currently trying to get the federal courts to get their children back into classes.

tional programs for the deaf, about the latest teaching methods being developed and about career opportunities for the deaf.

It is believed that parents throughout the state could be benefited greatly by receiving biweekly or monthly newslett with information from all for educating d

Pony Pass Motel
75 Main Street
KLAMATH FALLS, OREGON
Phone
(503) 884-7735

Additional informati retardation problems may be obtained from the following:

help on mental

- National Association for Retarded Children

The thrill sensed by ent of one of these children, that he should be here in the right place at the right time, that his child be one of the first to receive the possible benefits of DMSO cannot be described.

And now the devastating disappointment cannot be described nor can the frustration derived from the too often mire-bound mechanism of a stifling bureaucracy.

ne mothers of children who e retarded or otherwise disabled in learning, Mrs. Snyder said, quickly find that other people do not understand, and do not want to hear about it. She said that the group has been able to share a common understanding of their problems.

"It's a tremendous relief to be able to talk about it . . . it's been a very lonely road."

Myrna now hears, talks, understands and is learning to read. There are many problems unresolved, but when you realize she said her first word at 10 years, we feel she's come a long way since 1967.

There are now over 200 chapters of the National Society for Autistic Children all over the world. Information can be had by sending a stamped self-addressed envelope to NSAC c/o 169 Tampa Ave., Albany, New York 12208.

ents back to teacher

By RUSSELL KIRK

Although children are required to attend schools in every state, American courts repeatedly have ruled that parents, not school administrators, have primary control of the education of their children. But a good many parents have been wondering how far, in fact, they retain control over what children are taught.

The vast educational bureaucracy, increasingly centralized, is difficult for an individual parent to oppose, if he objects to the schooling given his child. And the increasing power of teachers' unions in most states, accompanied often by certain belligerent ideological attitudes on the part of officers of state and local affiliates of the National Education Association of the American Federation of Teachers, disquiets many parents.

Panel on children to meet

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